

STIGMA AND IDENTITY. THE SYMBOLIC MEANING OF SERIOUS MENTAL  
ILLNESS IN HEALTHCARE INTERACTION: TOWARDS A  
TRANSFORMATIVE AND TRANSACTIONAL THEORY

by

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## ABSTRACT

People with serious mental illness have been identified as having higher rates of mortality caused by medical illness compared to the general public. These high rates of medically related mortality have been linked to patient-related factors, provider-related factors, and system-related factors. Underlying many of these factors, the concept of stigma has been theorized to affect the healthcare that this population receives. The stigma of mental illness has demonstrated many problematic effects on basic social processes. Other stigmatized populations have demonstrated poorer health outcomes. The aim of this study was to address how the stigma of mental illness shapes the process of healthcare interaction for people with a serious mental illness by looking at the mindset that healthcare workers and people with serious mental illness have in regard to each other and the framework in which they interact.

A qualitative study was conducted to explore how mental illness as a socially understood concept was perceived to affect people with serious mental illness and their experiences with healthcare as well as nurses in an emergency room providing care for seriously mentally ill people. Nineteen people with serious mental illness were recruited from a daytreatment center and 8 nurses from an emergency department. Data analysis was conducted following the methods of grounded theory research.

The findings of this study support the stigma of mental illness as a social construct that affects healthcare as a socialized process for the seriously mentally ill

population. The stigma of mental illness is seen conceptually as something that acts internally to transform identity but is also something that acts dynamically through ongoing interactions with others. Beliefs about mental illness act to sensitize interaction between participants in healthcare, as people with serious mental illness have to interact with people who may view him or her as different, less capable, or incompetent. The caregiver is concerned about the possibility of being exposed to dangerous, abnormal, or unacceptable behavior. These elements transform the interaction and identity of both participants.

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## CHAPTER 1

### STIGMA AND IDENTITY: THE SYMBOLIC MEANING OF SERIOUS MENTAL ILLNESS IN HEALTHCARE INTERACTION

#### **Introduction**

Stigmatization has been suggested to create a person “whose social identity, or membership in some social category, calls into question his or her full humanity—the person is devalued, spoiled or flawed in the eyes of others” (Crocker, Major, & Steele, 1998, p. 504). This devaluation can develop into prejudiced behavior or negative stereotyping that represents the invalidating and poorly justified knowledge that results in discrimination (Rusch, Angermeyer, & Corrigan, 2005). The consequences of stigmatization can be pervasive and far-reaching, acting to limit access to important life domains, creating stereotype-consistent behavior, and threatening the social identity of the person at risk (Major & O’Brien, 2005).

Stigmatization has become an increasingly relevant topic in healthcare. Members of stigmatized groups have been shown to be at greater risk for health disparities, such as higher infant mortality and heart disease (Flack et al., 1995; Jackson et al., 1996), and they have poorer health-related quality of life following such illnesses as cancer (Hao et al., 2011). The health of stigmatized groups may be compromised through discriminatory practices like limiting access or providing substandard healthcare (Johnson-Askew, Gordon, & Sockalingam, 2011; Link & Phelan, 2001). Subjective



perception of stigmatization may also inhibit members of a stigmatized class from seeking healthcare due to anticipatory expectations of being devalued or discriminated against (Conner et al., 2010; Link, 1987).

People with a serious mental illness (SMI), such as schizophrenia or bipolar disorder, are thought to be susceptible to the stigmatization and discrimination that this label brings (Angermeyer & Matschinger, 2003). Many in the public still believe that people with a mental illness are dangerous and unpredictable (Angermeyer & Dietrich, 2006). Studies done in response to this societal belief have demonstrated that the stigma of mental illness is capable of negatively interfering with such basic social processes as obtaining employment (Stuart, 2006; Tsang et al., 2003), finding housing (Corrigan et al., 2003), or maintaining a support system (Link & Cullen, 1990).

People who internalize the socialized meaning of their stigmatizing conditions may suffer the consequences not only of public discrimination, but also of a damaging self-stigma (Corrigan & Watson, 2002). Self-stigma arises from an internal agreement with public stereotypes followed by a self-concurrence—a belief that these values apply to the individual—and finally a diminished self-esteem due to the effects of this system of beliefs (Corrigan, Watson, & Barr, 2006). Self-stigma has been cited as having a harmful influence on social adjustment (Perlick et al., 2001), morale (Ritsher & Phelan, 2004), self-efficacy (Corrigan et al., 2006), medication compliance (Sirey et al., 2001), and life satisfaction (Depla, Graaf, Weehgal, & Heeren, 2005; Rosenfield, 1997).

Together, public discrimination and self-stigma can create a situation that limits the seeking of treatment and ongoing participation in treatment (Corrigan, 2004). Because stigma from public and self is so likely to be attached to mental illness, the

Surgeon General of the United States identified stigma as the leading barrier for obtaining treatment for mental illness (US Department of Health and Human Services, 1999). Such stigma has also been shown to have detrimental effects for the mentally ill in connection with other areas of social interaction, such as interfacing with the criminal justice system (Teplin, 1984) and the general healthcare system (Desai, Rosenheck, Druss, & Perlin, 2002; Druss & Rosenheck, 1998).

The detrimental effects created by the stigma of mental illness have been inferred to play a role in the life-shortening process of mental illness (Allebeck, 1989). People with SMI have demonstrated a reduction in life expectancy of as much as twenty-five years compared to the general population (Colton & Manderscheid, 2006). While deaths from unnatural causes such as suicide and homicide account for a significant portion of decreased life expectancy in those with SMI, standardized mortality ratios show that death from physical illnesses are more than twice that expected in the general population, accounting for as much as two-thirds of the excessive mortality (Brown, Inskip, & Barraclough, 2000).

While research into the high mortality and morbidity from physical illness among the mentally ill have found several factors that create such a health disparity (Robson & Gray, 2006), little is known about how the stigmatizing nature of mental illness influences healthcare as a socialized process where interaction between participants is fundamental for optimal outcomes. The goal of this study is to improve understanding of how the stigma of mental illness affects interaction between people with serious mental illness and healthcare providers.

### **Purpose of the study**

This study addresses how the stigma of mental illness shapes the process of healthcare interaction for people with an SMI by looking at the mindset that healthcare workers and people with SMI have in regard to each other and the framework in which they interact. Through interviews conducted with people who have SMI and with nurses in an emergency room setting who have frequent contact with them, this study examines how beliefs are formed and maintained and what role this plays in healthcare as a socialized process of interaction. This study addresses the findings in the literature that infer that stigma plays a role in poor healthcare outcomes for people with serious mental illness.

### **Theoretical framework**

In order to understand how stigma influences the process of healthcare for people with mental illness and emergency room nurses who work with them, I use a perspective of symbolic interactionism to guide the methodology. This theoretical framework provides a structure for analyzing social interaction and individuals' selves—in particular how people create meaning during social interaction, how they present and construct the self, and how they define situations in the presence of others (Blumer, 1986).

Symbolic interactionism (SI) has its roots in the philosophical traditions of the early American pragmatism of Pierce, Dewey, and Mead. These theorists argued that the “self” must first be a study of the social organization from which “selves” are formed (Lewis, 1976). SI builds upon this idea and further infers the self as a lens through which the social world is refracted. The self emerges from the logic of social forms or social processes. Much of this activity is symbolic, involving construction and interpretation,

both within the self and between the self and others. This construction of meaning in interaction occurs by means of the ability to take on the role of the other or to put oneself in the position of the other, then to interpret from that position. Social interaction therefore becomes a process of construction that operates both to sustain established patterns of joint conduct and to open them up to transformation (Woods, 1992).

Blumer (1986) summarized the three premises that outline SI. The first premise states that human beings act toward things on the basis of the meanings those things have for them. Secondly, the meaning of such things is derived from, or arises out of, the social interaction people have with their fellows. Finally, these meanings are handled in and modified through an interpretive process used in dealing with the things the person encounters. These premises of SI create a basis for understanding social interaction and are informative for the interpretation of stigmatization theories, such as attribution theory and labeling theory.

Attribution and labeling theories outline a process by which the socially conceptualized nature of mental illness produces a stigmatized condition that follows the principles of symbolic interactionism. Both infer that a social process constructs a meaning for mental illness based on beliefs that arise out of interaction with others. For example, suicide, delusional thinking, or erratic behavior—all of which may be symptomatic of mental illness—can lead to ideas that people with SMI are unstable, irrational, or dangerous. These ideas are often based on the meanings that others ascribe to these behaviors and are passed on through interaction. These ideas may lead to stereotypes and become the basis by which discrimination or other outward behavior occurs. Furthermore, as individuals begin to see their own behavior not only from the

point of view of significant others, but also in terms of generalized norms, values, and beliefs—what Mead labeled “the generalized other” (Woods, 1992, p. 351)—an internalized sense of value is constructed based on this social framework. This internalized label becomes the foundation for interpreting other processes of public interaction. These models build on the basic idea that people act as they do because of how they define situations.

Interacting groups develop a large number of symbols that collectively constitute a culture or subculture (Woods, 1992). The symbols of mental illness are largely conveyed through media and often are represented in a negative manner. Popular movies, the news, and other media outlets portray the mentally ill as dangerous, unpredictable, and irresponsible. Mental illness is often attributed to drug and alcohol abuse and weak or immoral character. Such perspectives conclude that a person’s mental illness symptoms are under his or her control—in contrast to physical illness, where symbols are less negative in nature and are not viewed as behavior or lifestyle choices.

Following the guidelines of SI, mental illness and its impact on healthcare interaction can be viewed as a process that is shaped by social influences that create, and in turn deploy, a system of symbols. Understanding the meaning of these symbols for those who have mental illness and people who come into contact with them ultimately molds behavior and may lead to further understanding of the acknowledged health disparities for people with SMI.

### **Significance of this study to the healthcare field**

This study addresses how the socialized meaning of serious mental illness impacts healthcare as a social process by examining the perceived stigmatization of mental illness

in people with SMI as well as emergency room nurses who have contact with them. Emergency room nurses typically do not have a psychiatric specialty but have frequent contact with people who suffer from mental illness, as people with SMI are known to frequently use the emergency room (Merrick, Perloff, & Tompkins, 2010). Therefore, these nurses represent an ideal population of healthcare workers who are faced with the challenge of providing care to a highly stigmatized population.

Although studies in mortality and morbidity of people with SMI have focused on illness-related factors, unhealthy lifestyles, and problems accessing the healthcare system, few have attempted to determine how the social understanding of mental illness affects this issue. This study focuses on the demonstrated gaps in the literature surrounding how stigma plays a part in the poor outcomes of healthcare for the seriously mentally ill population.

This research endeavors to have both broad and specific implications for nursing by shedding light on how a socially discrediting condition can influence the process and outcome of healthcare. Through qualitative inquiry, SMI is examined both at the level of people with mental illness and that of emergency room nurses working with them to describe how SMI is socially constructed and demonstrated in healthcare interaction. This inquiry illuminates how healthcare professionals think and behave in response to contact with mental illness during healthcare contact.

This study also describes how a self-devaluing condition relates to receiving healthcare. In the same way the self-stigmatizing properties of mental illness have been shown to limit participation in several social activities, this study demonstrates that the stigma of mental illness can limit participation in healthcare. This study informs

clinicians of the need to further investigate the role of self-perception for people with SMI and how this may influence healthcare behaviors.

Another implication of this study includes extending and articulating the theoretical concepts of stigmatization. Through the use of symbolic interactionism, the representative meaning of mental illness is explored to investigate the underlying meaning of mental illness for both patients and the nurses who have contact with them. Symbolic interactionism provides a framework to analyze how people create meaning during social interaction, how they present and construct the self, and how they define situations in the presence of others. While theories of stigmatization have demonstrated these underpinnings to be helpful in understanding outcomes in several areas, the procurement of healthcare has not been addressed in this context.

## CHAPTER 2

### MEDICAL COMORBIDITY AND SERIOUS MENTAL ILLNESS

People with schizophrenia, bipolar disorder, and other major mental disorders known as serious mental illness (SMI) have demonstrated higher amounts of physical disease in comparison to the general population (Felker, Yazel, & Short, 1996). The impact of these high rates of comorbid physical illness has created excessive mortality in this population due to physical illness (Colton & Manderscheid, 2006). The causes for excessive mortality and comorbidity of physical illness in this population have been linked to patient-related factors, provider-related factors, and system-related factors (Viron & Stern, 2010). This chapter presents a systematic review of the literature related to the major medical problems of the SMI population by discussing morbidity, mortality, and the proposed causes of the high rates of medical illness in this population. It also addresses how the impact of medical illness in this population must be understood in light of social determinants of health.

#### **Mortality in the serious mentally ill**

Schizophrenia and other types of serious mental illness have long been observed to be life-shortening disorders (Allebeck, 1989) that cause excessive mortality despite substantial progress in ways of treating this population (Goff et al., 2005). People with serious mental illness have demonstrated higher risks for all causes of death compared to



the general population, including natural events such as disease and unnatural events such as suicide or homicide (Harris & Barraclough, 1998). The disproportionate amount of premature death has been recognized over many years, ranging from studies when psychiatric patients were housed in asylums to the present day (Lawrence, Kisely, & Pais, 2010). The life-shortening properties of SMI are demonstrated through measurements of standardized mortality ratios and years of potential life lost.

#### Standardized mortality ratios

The standardized mortality ratio (SMR) is a way of determining increased rates of illness or death by comparing observed deaths in a patient population with expected deaths in the general population (Newman, 2001). To determine the SMR, the number of deaths observed in a specific group is divided by the number of expected deaths in the general population. An SMR of greater than 1.0 indicates that the relative risk of death in the specific group is higher than that of the general population.

Serious mental illness has been shown to have increased standardized mortality ratios in several early studies. In a review of 66 papers on death rates for people with SMI published between 1934 and 1996, Felker et al. (1996) found standardized mortality rates for psychiatric patients between 1.7 and 4.2. The SMRs for unnatural causes, including suicides, accidents, and homicides, were from 2.5 to 26.6; those for natural causes were from 1.3 to 4.8. Examining 20 studies on mortality for patients with schizophrenia from 1966 through 1995, Harris and Barraclough (1998) found that patients with schizophrenia had an SMR of 1.6 with 2,938 excess deaths. The SMR from unnatural causes was 4.3 times that expected, accounting for 38% of excess deaths. Deaths from natural causes were 1.4 times more than expected, accounting for 62% of the excess deaths. The same

authors reviewed nine studies for bipolar disorder and concluded an SMR of twice the expected rate, with 368 excess deaths and a mortality risk nine times that expected, accounting for 54% of the excess deaths. Deaths from natural causes were 1.5 times more than expected, accounting for 46% of the excess deaths.

Recent studies continue to report elevated SMRs for patients with serious mental illness. Table 1 shows the results of several studies that looked at SMRs for patients with various mental disorders. The SMR for all deaths is at least twice as much as that of the general population. These studies and others like them are difficult to compare to each other because several factors figure into the equation, such as the follow-up period and age distribution. For example, in a study conducted by Pandiani, Banks, Bramley, and Moore (2002), the mortality risk for patients with a serious mental illness in the Vermont and Oklahoma state databases was shown to be significantly higher for the age groups 18 to 34 and 35 to 49, but not for age groups above 65. Other research has also shown that not only is the SMR for mental illness patients affected by age, but also by the type of illness as well as a first-degree family history of mental illness (Baxter, 1996; Laursen, Munk-Olsen, Nordentoft, & Mortensen, 2007).

High rates of deaths by unnatural means—such as suicide, homicide, and accidents—occur among all types of patients with SMI and figure considerably into the high overall SMR for patients with mental illness. For example, in a linked population study completed on a Danish psychiatric case register, 25% of patient deaths (17,892 out of 72,208) were related to an unnatural event, with the highest proportion related to suicide (Hiroeh, Appleby, Mortensen, & Dunn, 2001).

Table 1

## SMR and People with mental illness

Study	N	SMR	Unnatural SMR	Natural SMR	Population
Brown et al. (2000)	370	3.0	12.7	2.3	Schizophrenia
Enger et al. (2004)	1,920	4.4			Schizophrenia
Daumit et al. (2009)	2,379	3.7			SMI
Miller et. al. (2006)	20,018	3.2	12.6		SMI
Osby et al. (2001)	6,758 male	2.5	8.6	1.9	Bipolar
	8,808 female	2.7	12.7	2.1	
Osby et al. (2001)	15,829 male	2.0	9.8	1.5	Unipolar
	23,353 female	2.0	12.3	1.6	
Osby et al. (2000)	3,929 male	2.8	8.9	2.0	Schizophrenia
	3,855 female	2.4	10.3	1.9	

Using a record linkage study of Massachusetts Medicaid beneficiaries, Dickey et al. (2004) showed that mortality rates for those treated for a mental illness were about 2.5 times higher than those treated for medical disorders only. The authors found that the higher mortality rates could be explained by the number of injury-related deaths, such as homicide, suicide, accidents, and other injury deaths. A meta-analysis of several studies related to deaths in the SMI population reports an elevated rate of unnatural deaths for

this population: between 8 and 14 times greater than the general public (Harris and Barraclough, 1997).

While the rates of mortality related to unnatural causes are known to be excessive, the major causes of death in the SMI population are natural, such as cardiovascular disease and other types of prevalent medical problems (Hiroeh et al., 2007). Coronary heart disease, which occurs in about 33% of the general population (Hennekens, 2007), is the cause of as many as two-thirds of deaths for people with a serious mental illness (Hennekens, Hennekens, Hollar, & Casey, 2005). Brown et al. (2000) provide an example of this effect by looking at mortality rates in the SMI population. They conclude that although people with SMI have an SMR for unnatural causes of 12.7 and an SMR for natural causes of 2.3, 63% of the excess mortality was accounted for by natural causes.

Others studies also demonstrate substantial mortality due to physical illness in this population. Researchers examining rates of death following hospital discharge during a 3 year follow-up study in Denmark reported a 5.2% mortality rate, resulting in 226 deaths. Out of those deaths, 32% were directly related to physical illness (Salokangas, Honkonen, Stengard, & Koivisto, 2002). Reviewing several large and small studies for mortality rates in people with bipolar spectrum disorders, Roshanaei-Moghaddam and Katon (2009) found that people with such disorders had 35% to 50% higher mortality rates from natural causes. Such an increased mortality rate was stated as similar to the increased risk of mortality associated with smoking. These rates of natural causes of death are also seen to decrease the life expectancy in people with SMI as indicated through years of potential life lost from illness.

### Years of potential life lost

Years of potential life lost (YPLL) is a measurement of mortality that provides information about the risk of premature death. It is figured by using the difference between a person's age at death and the current life expectancy for living cohorts of the same age and sex. YPLL is always a positive value and approaches 0 at advanced age (Dembling, Chen, & Vachon, 1999). YPLL has been adopted as an alternative to standardized mortality rates for assessing the impact of specific causes of death (Gardner and Sanborn, 1990).

Studies examining YPLL and mental illness have demonstrated that not only do people with SMI have higher rates of medical illness, but they also have significantly lower life expectancy than the general population. Dembling et al. (1999) in a study through the Massachusetts Department of Mental Health found that patients treated for serious mental illness lost on average 8.8 years of potential life when compared to other people from the same state. A Swedish study examining the life expectancy rates for people with SMI showed that males lost an estimated 14 years of life and females lost 6 years compared to the general population (Hannerz, Borga, & Borritz, 2001). In a study linking patients admitted to an Ohio public psychiatric hospital between 1998 and 2002, Miller, Paschall, and Svendsen (2006) found that patients had a mean YPLL of  $32 \pm 12.6$  years.

The most encompassing study of YPLL and people with mental illness was reported in 2006 by Colton and Manderschied. This study used data from eight states and found that patients with serious mental illness died on average between 13.5 and 32.2 years earlier in comparison to the general population. The authors reported that overall,

people with SMI live an average of 25 years less than the general population and that 60% of deaths for the group of patients with schizophrenia was related to a medical condition. This high rate for premature death has been challenged by other research that has found lower YPLL when comparing patients with SMI to people with similar backgrounds. For example, Dickey, Dembling, Azeni, and Normand (2004) found that people with SMI from a Medicaid population database in Massachusetts had a mean YPLL of 34; however, when compared to Medicaid recipients without mental illness and a YPLL of 29 years, the net loss was only 5 years. Another study by Piatt, Munetz, and Ritter (2010) found that SMI patients of a community mental health system in Akron, Ohio, had an overall YPLL of  $14.5 \pm 10.6$ , compared with  $10.3 \pm 6.7$  for the general population of this area, leading them to conclude that while community mental health outpatients may have significantly different YPLL measurements than the general population, they may not be as high as those reported in the Colton and Manderschied study.

Although there may be disagreement on the exact overall rates of mortality and years of potential life lost for people with serious mental illness, there is little disagreement regarding the impact of mental illness in regards to health and well-being. The excessive burden of mortality is directly related to the high amounts of physical illness that are present in this population.

### **Medical comorbidity in people with serious mental illness**

High rates of medical comorbidity have long been associated with serious mental illness. In their review of medical comorbidity and mortality among psychiatric patients, Felker et al. (1996) concluded that patients with psychiatric disorders have high rates of

medical conditions. Known medical disorders afflict 50% of patients, and undiagnosed medical disorders affect 35%. One in five psychiatric patients has a medical problem that may be causing or exacerbating his or her psychiatric condition. More recent estimates have put the rate of comorbid medical illness between 50 and 90% (Gold, Kilbourne, & Valenstein, 2008). These medical problems include cardiovascular diseases, cancer, diabetes, and other illness.

### Cardiovascular disease

Cardiovascular disease (CVD), which includes coronary heart disease, stroke, and peripheral vascular disease, is the leading cause of death in the United States. In 2007, the overall death rate from CVD was 251.2 per 100,000 people, or 1 of every 2.9 deaths in the United States (Rogers et al., 2011). Cigarette smoking, hypertension, obesity, elevated cholesterol, diabetes, and physical inactivity have been identified in the general population as lifestyle risk factors for CVD in addition to factors such as gender, age, and family history of heart disease (Hennekens, 1998).

Cardiovascular disease has been cited as the chief cause of premature mortality among patients with SMI (Capasso, Lineberry, Bostwick, Decker, & St. Sauver, 2008; Hennekens, Hennekens, Hollar, & Casey, 2005; Roshanaei-Moghaddam & Katon, 2009). Depression, anxiety disorders, bipolar disorder, and schizophrenia have all been implicated as cardiac risk factors (Sowden & Huffman, 2009). Several studies have reported high prevalence of death due to CVD in the SMI population (see Table 2). Cross-sectional studies conducted on current patients with SMI also identify high rates of comorbid CVD.

Table 2

## Mortality of SMI patients due to CVD

Study	Total Deaths	Deaths from CVD	%	Rank
Dembling et al. (1999)	2214	755	34	1
Dickey et al. (2004)	190	68	36	1
Miller et al. (2006)	608	216	36	1
Piatt et al. (2010)	649	198	31	1

After interviewing adults receiving help through a community mental health program, Sokal et al. (2004) found rates of 30.4% for hypertension and 9.4% for other heart conditions. Jones et al. (2004) reported that 22% of Medicaid enrollees with SMI made claims for cardiovascular-related problems in Massachusetts between 1996 and 2000. Kilbourne, Brar, Drayer, Xu, & Post (2007) found that the prevalence rate for CVD diagnoses ranged from 3.6% (stroke) to 35.4% (hypertension) among patients being treated for schizophrenia at the Veterans Affairs (VA). This same study also noted that patients with schizophrenia were 19% more likely to have diabetes, 44% more likely to have coronary artery disease, and 18% more likely to have dyslipidemia than patients with bipolar disorder, suggesting an illness-related risk factor. In another cross-sectional study of VA patients with SMI, older patients were more likely to be diagnosed with cardiovascular conditions compared to younger patients (Kilbourne et al., 2005), suggesting an age-related risk factor.



The causes of these high rates of CVD are many; people with SMI have demonstrated a high prevalence of cardiovascular risk factors such as higher rates of smoking, poor diet, sedentary lifestyles, and obesity (Ferreira, Belo, & Abreu-Lima, 2010). These risk factors have also led to similar investigations into cancer as a comorbid cause for shorter life expectancy.

### Cancer

The American Cancer Society's 2010 report, *Cancer Facts and Figures 2010*, estimated that more than 1,500 people a day or approximately 569,490 people a year were expected to die of cancer in the United States. Additionally, cancer causes one out of every four deaths in the U.S., exceeded only by CVD. The American Cancer Society (2010) reported smoking as the largest causative factor for cancer, with other hereditary, environmental, and lifestyle factors following.

The findings on mortality and comorbidity for cancer in the SMI population have been mixed. Several studies have found lower mortality and comorbidity compared to the general population for all forms of cancer (Cohen, Dembling, & Schorling, 2002), including metastatic cancer and lymphoma (Carney & Jones, 2006), breast cancer (Barak, Levy, Achiron, & Aizenberg, 2008), nonrespiratory cancer (Osborn et al., 2007), and neoplasm (Colton & Manderscheid, 2006; Dembling, Chen, & Vachon, 1999; Miller, et al., 2006). Other studies, however, report cancer rates in the SMI population as similar to those in the general population (Hansen, Jacobsen, & Arnesen, 2001). Others have found higher mortality and comorbidity compared to the general population for breast cancer (Tran et al., 2009), neoplasm (Dalmau, Bergman, & Brismar, 1997; Dickey, Normand, Weiss, Drake, Azeni, 2002), and lung cancer (Brown et al., 2000; Capasso et al., 2008;

Lichtermann, Ekelund, Pukkala, Tanskanen, & Lonnqvist, 2001; Osborn et al., 2007; Tran et al., 2009).

These conflicting results appear in spite of known high rates among the SMI population of smoking (George et al., 2000), substance abuse (Goldman, 1999), obesity (McElroy, 2009), and other risk factors for cancer. Hypotheses for the decreased rate of cancers have included genetic determinants (Lichtermann et al., 2001), antitumor properties of antipsychotic medications (Cohen et al., 2002), or an underrepresentation of cancer deaths as early death due to other causes preceding the emergence of cancer, which generally occurs at later ages (Dembling et al., 1999).

Most of the data looking at cancer in the SMI population has looked at measurements of mortality. Lawrence et al. (2010) suggested that cancer mortality rates may not be an ideal marker of the risk for cancer because they are affected by patients' susceptibility to developing the disorder and by survival rates. The study reported that although population-based studies have not shown an increased incidence rate for many types of cancer, they have shown higher cancer mortality, suggesting a higher cancer case-fatality rate.

In an in-depth review of the research on the mortality rate of cancer in people with schizophrenia, Bushe and Hodgson (2010) concluded that while data in many of the studies were incomplete and that no single study or meta-analysis can be definitive, cancer—particularly of the lung and breast—was more common in people with schizophrenia, and almost as many people with schizophrenia die from cancer as from cardiovascular disease. They also reported that many of the risk factors for cancer among this population were preventable and that screening rates for cancer are inadequate.

Howard et al. (2010) reiterated that serious mental illness is associated with disparities in screening for cancer and with higher case-fatality rates. They suggested the higher rate of case-fatality was seen as partly due to the specific challenges of treating people with SMI, including high rates of other medical comorbidity, drug interactions, lack of capacity, and difficulties in coping with the treatment regimen as a result of psychiatric symptoms.

### Diabetes

The American Diabetes Association (2011) reported 25.8 million children and adults in the United States, or 8.3% of the population, have diabetes. This is an increase from a total of 20.8 million people, or 7% of the total population, reported in 2005 (American Diabetes Association, 2007). For the year 2007, diabetes was listed as the underlying cause on 71,382 death certificates and was listed as a contributing factor on an additional 160,022 death certificates. This means that diabetes contributed to a total of 231,404 deaths that year. Diabetes also creates increased risk for heart disease, stroke, blindness, kidney disease, neuropathy, and nontraumatic amputation (American Diabetes Association, 2011). Risk factors for the development of diabetes include increased age, obesity, family history, race, and a history of gestational diabetes (Goff et al., 2005).

The risk of diabetes for people with SMI is substantial because they represent a group at high risk for abnormal glucose homeostasis (Goff et al., 2005). In the Clinical Antipsychotic Trials of Intervention Effectiveness, patients with schizophrenia had a 13% rate of diabetes, compared to 3% observed in a random sample from the general population (Goff et al., 2005). Subramaniam, Chong, and Pek (2002) found a prevalence rate of 4.9% in a sample of 607 patients with schizophrenia who were using typical

antipsychotic medications. When a sample of those patients who were not diagnosed with diabetes were assessed through a fasting glucose level and an oral glucose tolerance test, 16% were diagnosed with diabetes (raising the total prevalence rate to 21%); 31% of patients were found to have impaired glucose tolerance. Mukherjee, Decina, Bocola, Saraceni, & Scapicchio (1996) found a 15.8% prevalence of diabetes in patients with schizophrenia, with an incidence of 12.9% for patients ages 50 to 59 and 18.9% for the group 60 to 69. In a review of records from a large third-party database, patients with schizophrenia were twice as likely to have been diagnosed or treated for diabetes compared to a control group within the same insurance company (Enger, Weatherby, Reynolds, Glasser, & Walker, 2004). In a study done by Srihari, Tek, Chwastiak, Woods, & Steiner (2007) to improve detection and management of diabetes at a community mental health center, the authors conducted a cross-sectional study of the prevalence and management of type 2 diabetes mellitus among patients receiving maintenance antipsychotic medication. Diabetes was more than 2.5 times as prevalent among participants (17.4%) as in the general population, with a rate of 26% for impaired fasting glucose. General estimates indicate that diabetes occurs in approximately 15% of people with schizophrenia (Holt & Peveler, 2005).

The comorbidity of diabetes for people with SMI has been of increasing interest, as several studies have suggested that the use of atypical antipsychotics may increase the risk for impaired glucose tolerance and diabetes (Kornegay, Vasilakis-Scaramozza, and Jick, 2002). For example, Henderson et al. (2000) found that 36.6 % of patients treated with Clozapine developed diabetes during a 5 year period of treatment. Koller and Doraswamy (2002) reported an increase in the development of diabetes during

antipsychotic therapy in the absence of weight gain and resolution of the diabetes after the antipsychotic was discontinued.

Other researchers have indicated that the risk of diabetes for people with SMI was observed before the use of antipsychotic medications; therefore, illnesses such as schizophrenia may be an independent risk factor for the development of glucose intolerance and diabetes. Kohen (2004) reviewed the early literature regarding diabetes and SMI, and noted several small studies and reports from the 1920s indicating abnormal responses to insulin and diabetes-like glucose tolerance curves. Studying a population of drug-naïve patients with schizophrenia, Ryan, Collins, and Thakore (2003) found that in a relatively young group with an average age 33.6 years, 15% of the participants had already developed impaired fasting glucose tolerance, compared with 0% from a matched healthy control group. Looking at the genetically linked factor for the development of diabetes, Lamberti et al. (2004) found that a cohort of schizophrenia patients without a family history of diabetes had a prevalence of type 2 diabetes of just 10%, compared to a cohort with a positive family history who had a prevalence rate of 33%. After reviewing recent studies on the prevalence of diabetes in patients with schizophrenia, Bushe and Holt (2004) concluded the following:

Evidence from studies published before the introduction of neuroleptic drugs showed a strong association between severe mental illness and abnormal glucose metabolism, and although this evidence must be interpreted with care because of the definitions used in these studies, it suggests that schizophrenia itself might be an independent risk factor for the development of diabetes. Reports of impaired glucose tolerance in young, drug-naïve individuals with first-episode schizophrenia add further weight to the argument that people with schizophrenia may be naturally predisposed to developing diabetes, and should therefore considered to be a high-risk group. (p. 70).

The presence of such high rates of diabetes in the SMI population becomes particularly worrisome due to the comorbidity of other illnesses. Diabetes has been shown to increase the risk for CVD by two to three times in men and three to six times in women (Hennekens, 1998). Insulin resistance with compensatory hyperinsulinemia are now considered to be risk factors for developing certain types of cancer (Simon & Balkau, 2010). Elevated blood glucose levels, which contributes to these and other illnesses, is seen as a modifiable risk factor that could potentially reduce the rates of such comorbid illnesses if controlled adequately (Danaei et al., 2010).

#### Other illnesses

Several other health problems have also been recognized when looking at comorbid physical problems within the SMI population. Rates of HIV infection have been shown to be elevated as much as 1.5 times in the SMI population compared to Medicaid recipients without SMI (Blank, Mandell, Aiken, & Hadley, 2002 ; Cournos, McKinnon, & Rosner, 2001). Hepatitis C infections have been reported as high as 8.1% for patients with bipolar disorder and 7.1% for patients with schizophrenia, compared to 2.5% of patients without SMI in a study by the VA (Himelhoch et al., 2009). Sokal et al. (2004) found 15% of patients with schizophrenia and 25% of patients with an affective disorder had chronic bronchitis, and 16% of patients with schizophrenia and 19% with an affective disorder had asthma. Patients with schizophrenia had more than twice the odds of suffering from asthma, more than three times the odds of suffering from chronic bronchitis, and nine times the odds of suffering from emphysema. Gupta et al. (1997) found an incidence rate of 19% for irritable bowel syndrome in patients with schizophrenia, compared with 2.5% in the general population. When using a patient

survey of 719 people with schizophrenia, Dixon et al. (1999) found the most common physical complaint was related to eyesight and dental problems.

The high rate of mortality and comorbid medical problems seen in the SMI population has been attributed to several factors. While each of these risk factors may contribute to the overall high rate of mortality, the presence of several risk factors in any one individual may create a synergistic effect, putting the individual at highest risk. Each category of risk factor provides an area for intervention, and interventions should be considered among all areas of risk. The categories of illness-related factors, individual and lifestyle factors, and system and social influences will be reviewed to describe the causes that contribute to the excessive rate of premature death and medical problems seen in the SMI population.

### **Illness-related factors**

Several factors related to serious mental illness and its treatment have been suggested as affecting the health of people with SMI. Serious mental illness often involves an overall or episodic reduction in the ability to perform the most basic of human tasks. Such general or episodic loss of function may be caused by psychosis or social withdrawal and may lead to neglect of self-care and physical health problems (Goldman, 1999). During acute phases, SMI may even be accompanied by denial or misinterpretation of telltale signs of medical illness (Sokal et al., 2004). Phelan, Stradins, and Morrison (2001) suggest that people with SMI may also be unaware of physical problems because of the cognitive deficits associated with SMI, and Jeste, Gladsjo, Lindmayer, and Lacro (1996) posit that people with schizophrenia are less likely to spontaneously report physical symptoms. Dworkin (1994) also reported that

schizophrenia has been associated with a high pain tolerance. These illness-specific factors may all affect a patient's awareness of the need for treatment or lead to a delay of seeking help when it is needed.

### Medications

The standard treatment for most SMI is medication. Psychotropic medications have been used for decades to treat the symptoms of mental illness. Recently, as the high rate of health problems in the SMI population has been observed, the use of atypical antipsychotics has been implicated as a possible risk factor for the development of physical problems.

Atypical antipsychotic medications have shown an impact on appetite regulation, causing carbohydrate craving and a feeling of “stomach emptiness” that persists after eating (Allison et al., 1999; Wirshing et al., 1999). The interactions of these medications with neurotransmitter receptors such as Histamine H1 and serotonin 5HT2C have been hypothesized to modulate eating behavior (Casey, 2003; Stahl, Mignon, & Meyer, 2009; Tardieu, Micallef, Gentile, & Blin, 2003), resulting in substantial amounts of weight gain by some patients taking atypical antipsychotics (Cascade, Kalali, Mehra, & Meyer, 2010; Meyer, 2001a). Many atypical antipsychotic drugs increase total and low-density lipoprotein cholesterol and triglycerides, and decrease high-density lipoprotein cholesterol (Melkerson, Hulting, & Brismar, 2000; Meyer, 2001b).

Use of atypical antipsychotics has also been associated with the development of higher rates of metabolic disorders compared to first-generation antipsychotic medications (Liao et al., 2009), which have proven to increase insulin levels and insulin resistance when used to treat SMI (Henderson et al., 2000; Melkerson & Hulting, 2001).



This insulin resistance may occur in the absence of weight gain with certain antipsychotics (Stahl et al., 2009). Newcomer (2007), in his review of atypical antipsychotic use, concluded that there are differences in the levels of risk for different atypical antipsychotic medications; he concluded that “based on substantial evidence that some treatments can increase adiposity, alter plasma lipids, and increase the risk of hyperglycemia, clinicians must be alert for potential negative effects on cardiometabolic risk” (p. 11).

### **Individual and lifestyle factors**

Although serious mental illness and its treatment may involve certain hazards, individual and lifestyle factors are great influences as risk factors for developing comorbid illness. In their review of factors contributing to medical problems in the SMI population, Brown et al. (1999) reported that people with schizophrenia have an overall “unhealthy lifestyle.” On a measure of five health indicators, Dickerson et al. (2006) found that only 1% of their SMI sample met all five qualifiers for good physical health. Increased amounts of smoking, substance abuse, obesity, hypertension, metabolic syndrome, and poor exercise and diet are noted in this population.

### **Smoking**

The American Cancer Society (2010) reported that tobacco is responsible for nearly one in five deaths in the United States, causing an estimated 443,000 premature deaths each year between 2000 and 2004. They also reported that 8.6 million people suffer from chronic conditions related to smoking, and more than half who continue to smoke will die from a smoking-related disease.

Approximately 75% of people with schizophrenia are smokers, compared to 25% of the general population (George et al., 2000). People with SMI smoke 44% of all the cigarettes smoked in the U.S. (Lasser, Boyd, & Woolhandler, 2000). Studies indicate they are heavier smokers, smoking more than 25 cigarettes a day (Kelly & McCreadie, 2000; Lawrence, Mitrou, & Zubrick, 2009); they also inhale more deeply and are exposed to higher levels of pulmonary toxins (Olinic, Young, & Freedman, 1997). They may also have more difficulty with smoking cessation in the short term and with smoking avoidance in the long term (George et al., 2000).

Psychiatric disorders themselves may predispose individuals to cigarette smoking (Tidey, Rohsenow, Kaplan, & Swift, 2005). People with SMI have high rates of smoking due to neurobiological, psychological, behavioral, and social factors (Robson & Gray, 2006). Smoking has been shown to alleviate certain symptoms and has been proposed as a modality of self-medication (Dalack, Healy, & Meador-Woodruff, 1998).

### Substance abuse

Substance abuse is a common problem for people with SMI; between 20 and 70% of patients with schizophrenia are diagnosed as substance abusers at some time during their lives (Goldman, 1999). The abuse of illicit substances in combination with SMI has repeatedly been found to lead to increased mortality rates (Dickey et al., 2004; Felker et al., 1996; Rosen, Kuhn, Greenbaum, & Drescher, 2008).

SMI patients with co-occurring substance abuse have significantly more medical illnesses. Substance abuse is associated with higher risks of cardiovascular disease (Gambarana, 2009; Hall & Degenhardt, 2009); in a study by Batiki et al. (2009), the prevalence of hypertension, chronic obstructive pulmonary disease, and coronary artery

disease was more than two times greater in the population of SMI with co-occurring substance abuse than the SMI without substance abuse. Substance abuse among the SMI also leads to a greater risk of cancer (American Cancer Society, 2010) and other illnesses, such as HIV (Brion et al., 2011).

Dickey et al. (2002) found that patients with schizophrenia and bipolar disorder who abuse substances had the greatest odds of developing five of the eight conditions they studied (diabetes, hypertension, heart disease, asthma, gastrointestinal disorders, skin infections, malignant neoplasms, and acute respiratory disorders) when compared to a control group.

### Obesity

Obesity is a highly prevalent condition with significant health implications. The general accepted definition for obesity is noted as a body mass index (BMI) over 30 kg/m<sup>2</sup>, while “overweight” is defined as a BMI between 25 and 29.9 kg/m<sup>2</sup> (Devlin, Yanovski, & Wilson, 2000). In the United States, 27% of the general population and 42% of patients with schizophrenia have a BMI  $\geq 27$  (Fontaine et al., 2001).

The health implications of obesity include increased rates of mortality and morbidity for hypertension, dyslipidemia, diabetes, CVD, certain types of cancer, and increased pregnancy complications (Devlin et al., 2000). Ekpe (2001) also recognized that obesity brings with it uncomfortable conditions such as snoring, sleep apnea, shortness of breath, joint pain, and psychological problems. Obesity is also associated with higher levels of mood and anxiety disorders (Simon et al., 2006).

Obesity in the SMI population has been recognized as a substantial problem. Gracious et al. (2010) demonstrated a 30% prevalence of obesity in a study among

adolescent patients with SMI, approximately double the rate of national and county norms. Dickerson et al. (2006) found rates of obesity in 20% of men and 27% of women with SMI, double the rate of the U.S. general population. Radke, Parks, and Ruter (2010) summarized that people with SMI are two to three times as likely to be obese as the general population, with reports that more than three-quarters of women with schizophrenia are overweight or obese.

Risk factors of the SMI population include genetic effects (Devlin, Yanovski, & Wilson, 2000), inadequate physical activity (Daumit et al., 2005), poor diet (McCreadie, 2003), and the use of atypical antipsychotic medications (Allison et al., 1999). While obesity in SMI patients results from a complex interaction of the genotype and environment of the person (Holt & Peveler, 2008), people with SMI have consistently demonstrated higher mortality from obesity-related conditions (Allison et al., 2009).

Because of the prevalence of obesity and related mortality among the SMI population, the National Association of State Mental Health Program Directors has recently suggested vigilant monitoring of weight parameters and aggressive approaches to weight reduction strategies in this population (Parkes & Radke, 2008).

### Hypertension and metabolic syndrome

Metabolic syndrome is a constellation of components that increase the risk for diabetes and coronary heart disease from 1.5 to 5 times (American Heart Association, 2007). Metabolic syndrome is diagnosed when three or more of the following are present: increased waist circumference ( $> 40$  in. for men and  $> 35$  in. for women), elevated triglyceride levels ( $\geq 150$  mg/dL), low high-density lipoprotein cholesterol ( $< 40$  mg/dL in men and  $< 50$  mg/dL in women), blood pressure  $\geq 130/85$  mm Hg, and fasting glucose

$\geq 110$  mg/dL (Newcomer, 2007). The 10 year risk of a first CVD event (such as myocardial infarction or stroke) in patients with metabolic syndrome is 16 to 18% (Hennekens, 2007).

Metabolic syndrome and its components are prevalent among the SMI population. In the U.S. hypertension affects approximately 19% of patients with schizophrenia (Dixon et al., 1999). In the Clinical antipsychotic trials of intervention effectiveness (CATIE), patients with schizophrenia had rates of hypertension of 27%, compared to 17% observed in a random sample from the general population (Goff et al., 2005). Hennekens (2007) reported that while metabolic syndrome affects 22% of the general U.S. population, the incidence is 41% among patients with schizophrenia. Male and female patients with schizophrenia in the CATIE trial were 138% and 251% more likely, respectively, to have metabolic syndrome than a matched group (McEvoy et al., 2005).

#### Exercise and diet

Exercise and diet are considered important modifiable risk factors for many medical problems. People with SMI have demonstrated overall unhealthy lifestyles characterized by poor nutrition and low physical activity (Brown, Birtwistle, Roe, & Thompson, 1999). In a study assessing nutrition and exercise behaviors among patients with bipolar disorder compared to those without SMI, subjects were more likely to report poor exercise habits, including infrequent walking or strength exercises; suboptimal eating behaviors, including having fewer than two daily meals and having difficulty obtaining or cooking food; and a weight gain of  $\geq 10$  pounds in the past 6 months (Kilbourne et al., 2007). Chuang, Mansell, and Patten (2008) assessed activity level and found that in an outpatient sample of SMI patients, two-thirds reported predominantly

sedentary routine daily activities. People with schizophrenia have been found to snack more often, consume instant meals frequently, and eat healthy groceries more rarely when compared to the general population (Roick et al., 2007).

In one qualitative study, outpatients of a psychiatric clinic reported that although they valued physical activity, they did not participate in physical activity because of mental illness symptoms, medication sedation, weight gain, fear of unsafe conditions, fear of discrimination, and interpretations of program compliance (McDevitt, Snyder, Miller and Wilbur, 2006).

### **System-related factors**

In addition high rates of medical disorders among the SMI, system-related factors also influence the high rate of mortality of this population. The healthcare system has been implicated as a major contributor to the high rate of physical health problems for SMI patients because it provides inadequate health care to this population (Phelan et al., 2001). Psychiatric providers have not been trained to address physical health issues or question whether health and wellness are feasible goals for people with SMI (Vreeland, 2007). Poor communication and coordination between providers in the physical and mental healthcare systems, geographic location, and financial reimbursement for providing services have also been cited as obstacles for people with SMI to receive treatment (Druss, 2007). Primary care physicians may also feel uncomfortable treating persons with SMI (Lester, Tritter, & Sorohan, 2005). Underutilization of medical services has been reported as a contributing factor to the relatively poor health status of individuals with SMI (Crews, Batal, Elasy, Casper, & Mehler, 1998; Druss, Rohrbaugh, Levinson, & Rosenheck, 2001).

Several specific factors have created obstacles in the pursuit of healthcare for the SMI population. These factors include socioeconomic disparity an associated a lack of health insurance, high rates of emergency room use, low rates of preventive care, and overall poor quality of care.

#### Socioeconomic disparity and associated lack of health insurance

People with SMI often have low socioeconomic status because of problems with education and maintaining employment (Eaton & Muntaner, 1999). Unemployment rates are reported as high as 72.9% in this population (Rosenheck et al., 2006). As a result of such large rates of unemployment in this population, many are faced with inability to obtain medical insurance or must rely on public insurance, such as Medicaid or Medicare.

Lack of health insurance has been cited as a leading factor in the SMI population for failure to participate in preventive healthcare services (Xiong et al., 2010). Economic constraints were also identified in a study by El-Mallakh (2007) as the most prominent reason for poor follow-up with diabetes care by a group of SMI patients with comorbid diabetes. Studies have indicated that even when persons with SMI have a primary care provider, they often delay treatment for economic reasons.

#### Emergency room visits

Many patients with SMI rely highly on the use of emergency rooms for health care (Hackman et al., 2006; Merrick, Perloff, & Tompkins, 2010). Dickerson et al. (2003) found that people with SMI are more likely to use the emergency room for medical problems than a matched group from the general population (37% compared to 20%). Studying emergency room use rates for people with SMI, Hackman et al. (2006) found

high emergency room use with the presence of a comorbid somatic condition as well as recent injury in the past 3 months, having a mood disorder, and being female. Another study by Salsberry, Chipps, and Kennedy (2005) showed that 69% of a sample of people with schizophrenia had an emergency room visit during the 2 year study period compared to 20% of people from the general population during the same time. Studying individuals with SMI using Medicaid insurance, Berren, Santiago, Zent, and Carbone (1999) found that they had a lower rate of healthcare claims compared to a similar group without SMI, but had a higher rate of claims for emergency rooms and ambulances. In patients with severe mental illness, 28% of the healthcare dollar went to emergency rooms and ambulances, compared to only 11% for patients without mental illness.

#### Preventive care

The rate of preventive care is also known to be lower in the SMI population. Studies have shown that patients with serious mental illness are less likely than the general population to receive outpatient preventive care services (Druss, Rosenheck, Desai, & Perlin, 2002). In a study looking at rates for women with schizophrenia and preventive care screening, researchers found lower rates of pap smear (40%) and mammogram (37%) compared to 67% for pap smear and 80% for mammogram screening in the general population (Salsberry et al., 2005). Despite clear guidance and a high prevalence of undiagnosed metabolic syndrome, screening rates for metabolic abnormalities in people with SMI remain low (Holt et al., 2010; Morrato & Newcomer, 2008). In part due to this lower use of preventive care, patients with SMI have higher rates of hospitalization due to ambulatory-care-sensitive medical conditions compared to the general population (Li, Glance, Cai, & Mukamel, 2008).



### Quality care

The quality of medical care for patients with comorbid physical and mental health disorders has been shown to be unsatisfactory in several areas (Mitchell & Malone, 2006). These deficiencies have been seen in the treatment of diagnosed hypertension and dyslipidemia (Nasrallah et al., 2006), assessment of CVD-related risk factors (Kilbourne, Welsh, McCarthy, Post, & Blow, 2008), and pharmacological management of CVD and diabetes (Kreyenbuhl et al., 2006; Kreyenbuhl, Medoff, Seliger, & Dixon, 2008) as well as decreased use of specialized revascularization procedures such as cardiac catheterization, percutaneous transluminal coronary angioplasty, and coronary artery bypass grafts following a major cardiac event (Druss, Bradford, Rosenheck, Radford, & Krumholz, 2000; Kisely, et al., 2007).

### **Health disparities and the stigma of mental illness**

#### Stigmatization of mental illness

The stigmatizing nature of mental illness has often been seen as a contributor to the barrier that many people with SMI face in seeking appropriate medical treatment. The consequences of stigma can be far-reaching and diverse. Its effects can be experienced on a number of different levels, including individual, familial, community, and societal (Rush, Angermeyer & Corrigan, 2005). On each different level, social pressures combine with cultural influences to shape the landscape by which stigma is created and continued, as well as what actions may follow. Prejudiced attitudes and discriminatory behaviors can create great costs to society, burdens to the community, and suffering to the individual. Of all groups of illnesses, psychiatric disorders have been

connected with some of the strongest social exclusionary and shaming practices throughout recorded history (Hinshaw, 2007).

### **Attributional model of stigma and mental illness**

Two models help explain how the stigmatization of mental illness can affect health care. The attributional model is based on a social psychology perspective described by Jones et al. (1984). This model proposes that a person is stigmatized from a mark that has been linked to a discredited disposition. The mark then initiates an attributional process in which people interpret other aspects of a person in terms of the mark and respond to stigmatized individuals at the expense of their individuality on the basis of their stigma. These marks exist on dimensions of concealability, course, disruptiveness, aesthetics, origin, and peril and may mediate the severity of the stigmatization process (Jones et al., 1984).

The attributional model further proposes that behavior is determined by a cognitive emotional process related to attributions made about the cause and controllability of a person's illness that further lead to inferences about the person's responsibility. These inferences lead to emotional reactions, which result in purposeful behavior (Weiner, 1995). This model holds that common stereotypes of the mentally ill, such as being dangerous or responsible for causing their illness, lead to negative emotions, discrimination, and avoidance (Link, Monahan, Stueve, & Cullen, 1999; Pescosolido et al., 1999).

Dangerousness continues to represent a key attribute related to the mentally ill. The perception that people who have a mental illness are dangerous is often perpetuated by media representations and sensational news stories (Klin & Lemish, 2008). Recent

studies continue to demonstrate the perception of the mentally ill as dangerous, violent, and unpredictable (Phelan, Link, Stueve, & Pescosolido, 2000). The link between dangerousness and mental illness is often cited as a reason for social distance from those with psychiatric illness (Pescosolido et al., 1999).

The perceived causality of mental illness has been shown to be the basis of discriminating behaviors compared to other stigmatizing conditions. For example, Weiner, Perry, and Magnusson (1988) demonstrated that individuals with mental illness were poorly liked, evoked less pity, and caused relatively high anger compared to people with physically based stigmas. Additionally, Martin, Pescosolido, and Tuch (2000) found that internal attributions for mental illness, such as “bad character,” led to increased social distance, while external attributions, such as stress, reduced social distance.

From these beliefs, people develop prejudiced attitudes toward the mentally ill, endorsing the negative stereotypes, generating negative emotional reactions, and leading to discrimination. This discrimination may take several forms, including coercion, segregation, or hostile behaviors. Discrimination may also appear as unwillingness to help or as active avoidance, affecting the extent to which persons with SMI are willing to engage in behaviors that lead to recovery. Social avoidance—the desire not to interact with people with mental illness—occurs as a person is labeled mentally ill and inferences are made related to his or her level of symptoms or perceived level of dangerousness (Corrigan et al., 2003).

The attributional theory of stigma is helpful in explaining how public stigmatization takes place. Using this theory, researchers have shown that the discrimination of the mentally ill has created problems for employment, housing, and

socialization (Farina & Felner, 1973; Penn et al., 1994; Martin et al., 2000; Wahl, 1999). In a study examining how stigma of mental illness compared with stigma related to being black, female, poor, or gay, Corrigan et al. (2003) found that 37% of the total sample felt they had been discriminated against; 73% of those felt the discrimination was due to their mental disability. The most frequently noted areas of discrimination occurred in employment (51%), housing (30%), law enforcement (26%), and education (22%). Research on the impact that stigma has on families with mentally ill members has also demonstrated similar burdens of social distancing practices (Angermeyer, Schulze, & Dietrich, 2003; Corrigan & Miller, 2004; Lefley, 1989; Struening et al., 2001).

#### Attributional model and physical illness in SMI patients

A review of the literature demonstrates that many factors can influence how the mentally ill receive care for physical problems. A number of studies have established evidence that medical professionals often display negative attitudes toward people with mental illness or their illness-related behavior. Studying attitudes of medical interns and residents toward psychiatric patients, Solar (2002) identified three major categories of difficulty: emotional difficulty with patient interaction, uncertainty about etiology, and management of pessimism regarding prognosis. Studying the stigma of mental illness among staff in a general hospital, Liggins and Hatcher (2005) found four major categories that were linked to tension created by patients and health professionals when dealing with the “uncomfortable relationship between the mind and the body” (p. 360). The categories include the themes of dangerousness, poor prognosis, disruptions of social interaction, and attribution of responsibility.

Fleming and Szmukler (1992) questioned 352 medical staff regarding people with mental illness. They found that these professionals widely blamed patients for their conditions. Additional traits such as homelessness, personal appearance, and social class were also felt to influence their attitude, creating “a multiple jeopardy.” In a qualitative study involving 10 nurses from a general medical unit caring for people with SMI, Reed and Fitzgerald (2005) found that half of the nurses expressed negative attitudes toward the patients. They identified a perception of danger, unrewarding care, lack of knowledge, and time constraints as shaping their attitudes. These studies and others (Aydin, Yigit, Inandi, & Kirpinar, 2003; Byrne, 1999; Manning & Suire, 1996; Mavundla, 2000) cited such reasons as difficulty communicating with patients, negative perception of their prognosis, uncertainty, attributing blame for their disorder, and lack of necessary skills as determinants for negative attitudes of practitioners.

### **Labeling model of stigma and mental illness**

A second model of stigmatization demonstrates how the label of mental illness may lead to a process of self-stigmatization. This model, first introduced by Scheff (1966), describes a process by which an individual internalizes socializing attitudes regarding mental illness. Once labeled, the individual becomes subjected to uniform responses from others. Behavior is then crystallized into conformity to these expectations and stabilized through a system of rewards and punishments that constrains the labeled individual to the stigmatized role. The ultimate result of this model is an individual suffering from a chronic mental illness.

The labeling model has received high amounts of criticism due to the suggestion that a chronic mental illness is the result of a socialized process (Link, Cullen, Frank, &

Wozniak, 1987), and modified views of this model have been proposed (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). These approaches continue to rely on the idea that individuals internalize societal conceptions of what it means to be labeled mentally ill. Through the process of socialization, individuals learn the attitude of the community toward the mentally ill and internalize these. The attitude of the community toward the mentally ill is often formed through representations in the media and news rather than through individual experiences with the mentally ill. The individual also becomes aware of the extent to which people believe that the mentally ill will be devalued and the extent to which they believe that they will be discriminated against. As an implication of this reasoning, the individual's expectations of rejection are an outcome of socialization and the cultural context rather than the pathological state, as Scheff proposed. Once an individual receives the official label of having a psychiatric illness by diagnosis, the socialized views toward the mentally ill become personally relevant. People then respond to the label by concealing their illness, withdrawing from social interaction, or attempting to educate others to ward off negative attitudes.

The consequences of internalized stigma can have detrimental effects on an individual. If the person believes that others will discriminate against or devalue him because of his status, he may withdraw as a protective measure (Crocker & Major, 1989). The individual may feel shame or believe that he or she is set off from others and thus is very different. These responses lead to constricted social networks, fewer attempts at job-seeking, and limiting life chances (Link et al., 1989). For example, patients diagnosed with bipolar disorder who had concerns about stigma demonstrated significant

impairment in social and leisure functioning. Patients used avoidant coping strategies in anticipation of rejection by individuals outside their families (Perlick et al., 2001).

The concept of internalized stigma has been cited as a major factor as to why people delay obtaining help or do not seek psychiatric treatment (Brown & Bradley, 2002; Gary, 2005; Komiya, Good, & Sherod, 2000). This self-perceived stigma of mental illness has been found to affect self-esteem (Blankertz, 2001; Link, Struening, & Neese-Todd, 2001), self-efficacy (Corrigan et al., 2006), social adjustment (Perlick et al., 2001), medication compliance (Sirey et al., 2001), morale (Ritsher & Phelan, 2004), and life satisfaction (Depla et al., 2005; Rosenfield, 1997).

#### Labeling model and physical illness in SMI patients

Research studies have indicated that internalized stigma leads to a decrease in participation in healthcare or a negative view of the healthcare experience (Mansouri & Dowell, 1989). DeCoux (2005) reported psychiatric patients often delayed or avoided seeking treatment due to their perception that their complaints would not be taken seriously, waiting for objective symptoms to become so apparent that a provider would be able to corroborate their subjective complaints. Liggins and Hatcher (2005) found that people with mental illness in a general hospital setting felt that their label affected the way others responded to them. The patients believed they were treated differently, negatively judged, and often ignored. These experiences often translate into expectations that future concerns will be invalidated. Hahm and Segal (2005) found in their study that one in two participants with SMI think they should have gone to a healthcare provider but did not; they observed that SMI individuals often avoided healthcare for fear of coercive treatment. These examples of findings on the consequences of the label of mental illness,

coupled with the prejudicial effects of the stigma for mental illness, show the double jeopardy for the consumer when seeking care for medical problems.

Stigma affects both individual and system influences on physical health for people with SMI. The stigma of mental illness plays a role in determining how people are viewed and treated in the arena of healthcare, as well as how medical providers are viewed and approached by people with SMI. By improving practices that address how stigma shapes and influences healthcare for people with SMI, researchers and healthcare professionals may improve outcomes on mortality.

### **Conclusion**

The seriously mentally ill population has demonstrated a high amount of mortality and comorbidity related to physical illness. The prevalent conditions of cardiovascular disease, cancer, diabetes, and other illnesses seen in this population shorten the life span of and increase medical mortality for people with SMI. The health disparity seen in people with SMI is created by illness-related, individual, lifestyle, and system-related factors. The stigma of mental illness is seen to influence healthcare through attributional and labeling effects, which act to reduce positive healthcare contact. While research has provided invaluable understanding of this complex process, there are many gaps in the comprehension of the problems that result in premature deaths for those with SMI. Further studies need to address how interventions can be used to target the factors that create the health disparity seen in the serious mentally ill population.



## CHAPTER 3

### HEALTHCARE INTERACTION AND PEOPLE WITH SERIOUS MENTAL ILLNESS

#### **Introduction**

Belonging to a group or category of people associated with a socially undesirable trait can lead to becoming a target of negative social beliefs, prejudice, and public discrimination (Goffman, 1963). Self-recognition of having such undesirable qualities or affiliations can also lead to a process of self-stigmatization whereby one may internalize the beliefs and values of society and react by devaluing oneself, just as society devalues the undesirable trait or group (Corrigan, 2005).

The process of how individuals come to view themselves in relationship to others as constituted by society is described in Tajfel, Billig, Bundy, and Flament's social identity theory (1971) and Stryker's role identity theory (1980). While these theories differ in several respects, each views a person's identity as differentiated into multiple identities that are formed through social interaction in various groups or roles (Hogg, Terry, & White, 1995). Identity formation from belonging to a group or role is mediated through a process of salience or activation of the identity, depending on the context of the situation or a commitment to the role (Stets & Burke, 2000).

Understanding the concept of identity formation for people with a serious mental illness is important, because mental illness has been highly associated with both public

and self-stigma (Corrigan & Watson, 2002). Research has shown that having a mental illness has demonstrated negative effects on self-esteem (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Wright, Gronfein, & Owens, 2000), self-efficacy (Corrigan et al., 2006), overall quality of life (Graf et al., 2004), and activities such as socialization (Moses, 2010), work, and education (Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). .

Healthcare, a process that is influenced by social pressures, is also an area where the stigma of mental illness has been considered as affecting the outcome, just as ethnicity and race (Casagrande, Gary, Laveist, Gaskin & Cooper, 2007; Trivedi & Ayanian, 2006), low socioeconomic status (Loignon et al., 2010; Wamala, Merlo, Bostrom, & Hogstedt, 2007), and obesity (Kaminsky & Gadaleta, 2002) have been implicated in lower healthcare participation as a result of anticipated stigma from healthcare providers. People with mental illness have also shown a disparity in receipt of quality healthcare (Mitchell, Malone, & Doebbeling, 2009).

This first part of the study seeks to address how people with serious mental illness incorporate the stigmatizing nature of mental illness into their self-concept and how this affects the context of interaction with healthcare providers. This analysis is part of the larger dissertation study that looks at how stigma affects the interaction between people with serious mental illness and healthcare providers.

## **Methods**

This is a qualitative investigation into how the stigma of mental illness shapes healthcare interaction. Qualitative research is ideal for studying this problem because it is a way to gain insight by discovering meanings of experiences and improving

understanding of the whole (Burns & Grove, 2001). Exploring this subject with a qualitative methodology allows for careful investigation into the beliefs that lie beneath social behavior and therefore acts to increase understanding of this problem. This study uses a symbolic interactionist perspective to guide the methodology. Symbolic interactionism provides a structure for analyzing social interaction and individuals' selves, in particular how people create meaning during social interaction and how they present and construct the self, as well as how they define situations in the presence of others (Blumer, 1986).

### Participants

Subjects for this study were obtained through the University of Utah as well as the Utah Department of Health and Human Services. All subjects voluntarily agreed to participate and consented to involvement in this study consistent with the practices outlined from the respective institutional review boards.

People with SMI were recruited for this study from a day-treatment center operating under a community mental health treatment center located along the Wasatch Front in the state of Utah. The day-treatment center is located in a rural city; clients of the community mental health treatment program have opportunities for extended daytime contact with staff and peers to provide support, socialization, therapy, and recreation. Attendance at the day-treatment center is voluntary and participants attend as frequently as daily or as seldom as once or twice a week. Patients are required to have a serious mental illness in order to take part in this level of care. During an average day, approximately thirty-five to fifty patients will attend the facility at some point.

Recruitment for this study was done by means of a flyer explaining the study parameters and asking interested individuals to contact the investigator via telephone or email. Staff at the day-treatment facility also announced the opportunity to participate in the study. In order to participate in the study, participants were required to have a serious mental illness such as schizophrenia, bipolar disorder, or another psychiatric condition that led to substantial impairment in their functioning. Participants also agreed to be interviewed and audio recorded. Subjects were allowed to participate if they did not want to be audio recorded. Prior to participation in the study, the subjects reviewed the consent form and were assessed for their level of understanding of what they were consenting to by answering questions on what they felt the purpose of the study was, what they understood the risks to them were, and what they were required to do to participate. If subjects demonstrated lack of significant understanding of these questions, they were not allowed to participate. Denial of consent to participate was also an exclusion criteria. Subjects were given a \$25 gift card to a local store for taking part in the study.

Participants for this study included 11 women and 8 men, age 26 to 56 years old. All subjects were able to verify a level of comprehension of the study's purpose, risk, and requirements to a satisfactory level and each member of the study consented to be audio recorded. Subjects self-reported at least one diagnosis of serious mental illness, and often several different diagnoses. One person reported having been in mental health treatment for less than a year, but all other participants reported being in treatment for many years.

#### Data collection

Data for this study were obtained by interviews conducted over a course of several weeks. Interviews were conducted in an office at the day-treatment center that

was allocated by the facility. Each interview was between 30 and 60 minutes in duration and was conducted by the primary investigator. The participants were interviewed individually using an open-ended format that asked them to describe their experiences and perceptions of how having the label of mental illness influenced their interactions with others, including healthcare providers (see Appendix A for sample questions).

The opening questions concentrated on background information, such as type of illness and amount of years in treatment. Later questions focused on subjects' perceptions of how having a mental illness has changed how they view themselves, as well as how others who know about their mental illness view them. These questions were followed by how the label of a mental illness shapes interaction with others, especially medical providers.

Initial interviews helped to define the context of the issue; later interviews were used to clarify and gain further understanding of the issues that were raised. After the interview was completed, all subjects were given an opportunity to ask further questions or clarify any of their responses.

### Data analysis

The research methods of grounded theory (Strauss & Corbin, 1998) were used to conduct this study. Grounded theory methodology consists of a systematic yet flexible set of guidelines for collecting and analyzing qualitative data to construct theories grounded in the data (Charmaz, 2006). Grounded theory begins by constructing data through interviews and observation, then taking this data and analyzing it through a means of coding.

Beginning with the first interview, all recordings were transcribed and analyzed using NVivo 8, a software package for qualitative research analysis. Transcription was completed by the primary investigator and reviewed for accuracy. Following the transcription process, an initial memo was written about the overall impression of the data, areas that needed further exploration, and any relevant codes or domains that were apparent. Open coding procedures, which consisted of labeling each statement by a participant and comparing it with statements from other subjects, were accomplished for the first interviews. During this initial coding phase, concepts were grouped by unifying themes and generating categories. Several memos were written and used to interpret the data as well as figure out what areas needed exploration in future interviews. Following the open coding, the process of relating categories was used by identifying the conditions under which the studied problem occurs and how people respond. This higher-level coding procedure, defined as axial coding, helped to refine categories and explain relationships.

It was at this time in interviewing that saturation occurred (Polit & Beck, 2004); interviews began to reveal redundant information, no new data were obtained, and interviewing stopped. Major categories were selected through a final selective coding procedure that helped to integrate and specify possible relationships between categories and construct a set of relational statements to explain the area of study.

## **Results**

The principal finding of this study is that the stigma of mental illness works to create an identity for the person with mental illness that in turn acts to define and change interactions with medical providers. This finding is supported by the themes of mental

illness as “a transformative identity construct” and mental illness as a “transformative identity in healthcare interaction.”

Mental illness as a transformative identity construct is seen as a socialized concept that acts to change a person’s identity through a process that incorporates beliefs about mental illness into a view of one’s self through understanding of mainstream beliefs, contact with significant others, and contact with other people who have SMI. This identity shapes interaction by sensitizing a person to the negative stereotypes that exist and results in strategies such as concealing, limiting disclosure, maintaining physical appearance, and judging others as worse off as a means to deflect the negative features associated with one’s transformed identity.

Serious mental illness as a transformative identity in healthcare interaction is seen as an identity that changes the nature of healthcare interaction by creating a perception that medical providers treat a person with mental illness differently; providers get distracted by the mental illness and feel that the patient is less competent or seeking drugs. People with SMI use strategies such as avoiding healthcare contact until symptoms are obvious and changing medical providers. Medical providers that are seen as accepting of mental illness, willing to spend time with the patient, and empathetic are able to facilitate positive healthcare interactions.

### **Serious mental illness and identity transformation**

The social world for the person with SMI is made up of individuals who share the reality of what it is like to be identified as having a mental illness and the distinction that goes along with it. This social domain organizes people of various backgrounds, interests, and knowledge bases behind the mutual understanding of how the concept of mental

illness—which carries a distinguished meaning in society at large—can affect them on a personal basis. Interaction with this social world creates changes in identity for the individual and forges a perspective by which interactions with others may be defined.

Estroff and colleagues (1991) described the transforming character of serious mental illness on one's identity as a process that begins when a person comes into contact with mental health treatment and proceeds through an indeterminate course. This process begins when a person is met with the burden of having to acknowledge serious mental illness through the assignment of a psychiatric diagnosis. The experience of initial contact with mental health treatment and designation of mental illness leads to either refusal to accept the label of illness through a process of disputing its reality, usually by attributing symptoms to other causes, or acceptance of such a label. Identity formation further changes as people deliberate between differing perspectives of mental illness and adapt to the realities of having the illness (Roe & Davidson, 2005). Identity transformation can also involve a process whereby a once-valued person is transformed into someone who is dysfunctional and devalued, first by others and then by themselves (Estroff, 1989).

The work of this study extends the premise of these earlier theories regarding how people subjectively accommodate aspects of mental illness into their identity by also demonstrating understanding of how identity is changed through intersubjective experiences, such as encounters with medical providers. These encounters can act to change the identity formation process for both the individual with mental illness and the medical provider.



### Personal accounts of stigma and identity transformation

Having serious mental illness has a compelling effect on how people view themselves. The effect on a person's identity can occur from the initial contact with mental health treatment, although the actual condition may have been happening for some time prior to this contact. Several participants of this study cited having difficulty with mental health symptoms for quite some time before formal connection was made with the mental health system. A common experience expressed by many participants in this study was the sense that something was wrong in their lives long before treatment was sought. By comparing themselves to others, a self that was flawed was revealed by a feeling that they did not belong or that they were different from their peers in some unusual way. Looking back on their lives, many subjects of this study felt they were characterized as being someone with a mental illness although the formal label may not have been given until years later. For example, one individual described:

I think I had mental illness starting at about age 15, but I didn't know it until I was about 22. I didn't start getting treatment for it until I was about 24 . . . I didn't really realize how it affected all of our siblings in my family and me. I was just confused and I thought people work on strange behaviors and I didn't understand anything about it.

The difficulty experienced by several subjects was in part related to the uncertainty of why they behaved the way they did and the lack of a framework to explain these behaviors. One individual's description was characteristic of several who reported similar thoughts about their preidentified illness: "I just thought I was crazy, especially with the OCD things. I just thought I was crazy or just weird. I really didn't know what it was." Other patients' views contrasted this preidentified state with memories of a time in which they functioned highly and expectations were at a much higher level:

I had such high expectations for myself. I was always the overachiever and when I had my nervous breakdown at 19 it just unraveled everything. It unraveled plans for my whole life and I lost so many things by that breakdown. I haven't regained that status in my head, that overachiever status that I liked. I enjoyed being the overachiever and the honor student, being on the dean's list; I liked that, and I haven't achieved that again. Although some subjects articulated a clear delineation between when they felt well and when they became mentally ill, most subjects identified a significant period of time, if not their entire life, where something was wrong or different in the way they felt or behaved. Such individuals looked at this as a time where they were still ill, but undiagnosed, whereas others looked at this as a time where they were higher functioning, a time they would never recapture.

The different ways subjects looked at their lives prior to formal contact with mental health treatment helps emphasize the complex symbolic meaning that mental illness may have. On one hand, the diagnosis of a mental disorder may provide a sense of relief by providing an explanation for thoughts, feelings, and behavior that are not well understood. Mental illness symbolically represents an understanding of these issues by providing a label that explains the thoughts, feelings, and behaviors and allows for such issues to be explained in a framework of illness, rather than a defect of character or other reasoning. On the other hand, mental illness can symbolically represent a turning point where an individual changes from a functioning person with high expectations to someone of a different status with the low expectations that come with illness. Mental illness also becomes symbolic as a condition that separates an individual from the rest of society or from those without a mental disorder. This diversity in the symbolic meanings associated with mental illness demonstrates the challenge that people with SMI can have in coming to terms with their condition and incorporating it into the understanding of

their social identity. In addition to the symbolic representation that SMI has, the incorporation of this construct into a person's identity has many influences, beginning with a set of beliefs about mental illness prior to acknowledgement of one's illness.

### **Pre-illness beliefs**

Participants of the study talked about their beliefs about mental illness before they were diagnosed. The majority of subjects acknowledged the influence of media stereotypes as influential on their perception of mental illness. Common stereotypes that were recognized came from movies such as *One Flew Over the Cuckoo's Nest*, *Benny and Joon*, and *The Dream Team*. Subjects described these media stereotypes as portraying "mental illness as horrible—something awful," or exaggerating the negative aspects as showing "the worst stuff you can have." Such misleading and inaccurate portrayals have typified mental illness as it is often seen in media representations (Klin & Lemish, 2008).

When asked to describe their beliefs about mental illness prior to their own diagnosis and treatment, most either identified having no knowledge about mental illness or identified an understanding that was associated with a negative or derogatory meaning. Reconciling these beliefs about mental illness with one's own identity as mentally ill becomes a significant task over time, as this individual explains:

The media influenced me; I don't ever remember hearing my parents say anything negative about people with mental conditions. I learned it through the schools and the media. . . . I used to think that people who went to mental institutions were crazy, out of control, violent, or they were slime. Now look what's happened to me. Here I'm in this situation for 31 years that I hated, talked negatively about, and now I'm in it, so that's how it is sometimes in life.

Some subjects in this study also acknowledged having contact with mentally ill people prior to their own treatment. The contact was described in negative terms and demonstrated attitudes and actions that reflected the negative beliefs that are often connected with mental illness:

Before I was diagnosed with my illnesses, I would see a lot of people who were depressed or unable to go out and hang out in town or do things. I couldn't understand it and it did throw me off sometimes. I wouldn't want to hang out with them because I didn't understand it. . . . I realize where I was before and where I am now and I look back at some of these people and I realize I used to be like that, I used to be scared to be around people who had depression. . . . I generally stayed away.

This awareness of the dominant perspective from members of the marginalized group provides a dual understanding of the social meaning of mental illness. Not only is the perspective of one who possesses this attribute understood, but the view of one who is not mentally ill is also understood. The view gained while looking at the group from the outside (non-ill) perspective reflects the view of society at large and becomes a point of reference from which the now-ill person draws on to make sense of his or her current position in society. Having this understanding of the majority, or non-ill group, allows people to position themselves in society and reflect on how they are to be looked at and treated by others. This ability to view one's self from the perspective of an outside member leads to the continual process of defining and redefining one's position based on ongoing interaction with one's significant others and society in general.

### **Contact with mental health treatment**

Contact with mental health treatment becomes a poignant influence on identity transformation. In most cases, formal contact with the mental health system was achieved through persuasion by family or friends, recommendation from medical providers, and in

some cases through the legal system, although a number of individuals sought out treatment on their own due to their inability to tolerate symptoms further. Formal contact with the mental health system is described as taking place in a treatment facility. Individuals identified facilities as “the hospital,” “my doctor’s office,” and the mental health center where they received a conventional diagnosis of a mental illness. The term *mental institution* was also used on several occasions to describe where treatment contact occurred, revealing an antiquated or dramatized representation of a place where people are locked away, similar to that of an incarceration site rather than a treatment facility.

Because pervasive societal beliefs shaped the primary way of viewing mental illness prior to treatment, fear permeated the process of treatment contact, as exemplified by one person’s initial contact:

It started out in Oregon; I spent some time at their state facility. . . . I remember being scared of what I thought I knew. They put me in the hospital and then I started guessing what is wrong with me. . . . I think it was a shock to me how I was put in the hospital in the first place. . . . I was pretty high on life. I was slightly homeless and I thought everything was fine. . . . I didn’t know why they were taking me to a hospital but they had been on the phone with my mother and she kind of gave the okay for that to happen . . . They stuck me with some Haldol and put me in a bed and I spent two and a half months there.

Fear also figured into the initial contact because people knew it would create a means of identity transformation. Subjects discussed having concerns about how others would look at them once contact was made with the mental health system. This fear has been identified by the Surgeon General of the United States (1999) as the leading obstacle for obtaining treatment of mental illness. One woman talked about how others began to treat her after she attempted suicide: “[People start] not talking to you or kind of shunning you like you are contagious or something. . . . People don’t sit next to you

anymore, they don't talk to you." Treatment contact becomes especially difficult when viewed from the perspective of how it may affect one's standing in society and facilitate movement into a socially defined category of a lower-status individual.

### **Contact with significant others and identity transformation**

Treatment contact and the subsequent labeling involved raise an awareness among other people significant to the individual and promote further identity transformation through interaction with people such as family and friends, as well as others with whom one associates through treatment. The stereotypes of mental illness begin to take on more personal meaning as the individual begins to be known as someone with a mental illness. One woman's recollection of how others perceived her once she was diagnosed describes the transforming nature of the diagnostic label of mental illness:

Some part of me [said] there is a name for what I'm going through, but all of a sudden instead of me just having a bad day, just like everyone else . . . no, there's a label; no, you have depression; and all of a sudden I felt this huge label and stigma . . . all of a sudden anything you do gets attributed to your mental illness; when something totally unrelated happens . . . my family will say, "Oh, its your OCD," or "You're just emotional because of your depression," when it's a valid feeling or just a quirk I have that has nothing to do with OCD or anything. You know, it's just like something anybody would have, but it gets lumped back to my mental illness, where before they wouldn't have done that.

The inclination to act toward a label rather than the individual is a significant issue for many people with SMI. This labeling effect acts to lessen the importance of individual qualities that make up a person's identity and assigns them into broad categories whereby judgments are cast based on the societal understandings of such conditions.

The diagnosis of a mental illness represented a label that for most patients was often spoken of in terms of how it affects their behavior, way of thinking, and so on at a

particular time or situation. However, one patient identified a more pervasive sense of identity linked to her mental illness:

I'm definitely in the "I am" category. You know, the "I am mentally ill" rather than the "I have a mental illness" category. I would say it is a big part of how I define who I am. . . . I think mostly because it's been a part of me for almost my whole life.

In contrast to this individual, most patients described their diagnosis as a part of who they are as opposed to a dominant piece of their identity. The label of mental illness was often described as "my diagnosis" and was used to describe behaviors and ways of thinking during a discrete period of time or episode of behavior. For example, one woman described episodes of her mental illness as follows:

One of the things I do when I am manic is spend money, so I have debt that I really regret . . . debt for things I wouldn't have bought if I had been myself. . . . My biggest regret has to do with my family, that they have to go through me being that way and there is not really anything I can do about that.

This way of framing the disorder helps the individual categorize distinct behaviors related to the mental health condition that can occur in relation to time and situational factors. These mental illness-related behaviors are often described as having marked beginnings and endings rather than being a continuing process, and are affected by a number of circumstances, as this person describes:

I think of my PTSD as a package that is kind of like a little surprise package or gift package; there's something you usually get in it, maybe flashbacks or nightmares or anxiety, and then there's maybe some extra things, like alcoholism, or the Xanax addiction . . . it varies over time, it's not a consistent thing. I think of it a lot like my asthma, that sometimes it flares and needs some settling, and then I can go through a period of time where it's really stable, and over time I get to know my triggers, like with asthma, and I know what's worked in the past, and I can control my environment somewhat, so it's really similar in a lot of ways to how you manage any other chronic condition.

Being able to frame certain behaviors as related to one's mental illness allows for a distinction to be made between such behaviors and what the individual feels is his or her identity. This ability to separate mental illness-dependent behavior and otherwise normal behavior allows one to see oneself as a person with a mental illness who at times acts as such a person, but otherwise is able to maintain a commonplace existence. In line with this way of reasoning, a person with SMI is able to formulate his or her identity or see himself as one who has a mental illness, but in all other aspects is relatively the same as other ordinary people, carrying many different identities, such as spouse, employee, student, friend, and so on. Some researchers have suggested that this type of explanation for one's mental illness may act as a means to protect identity.

Using a grounded theory approach, Sayre (2000) found that psychiatric inpatients attributed hospitalization as a response to a "life crisis" as a means to lessen the stigmatization of the experience, instead of identifying themselves as members of a group of mental health patients. Others have hypothesized that people with SMI may see their identity as mentally ill only when it is appropriate given a certain context (Hall & Cheston, 2002). This way of framing one's identity as salient given a circumstance resonated with the findings of this study and allowed people with SMI to utilize a number of ways to disclose or hide their mental illness from others, including health care providers.

### **Contact with others with SMI and identity transformation**

Participation in mental health treatment also promotes the process of identity transformation through contact with others who share common experiences and understanding of what it is like to live with a mental health condition. Treatment for



mental illness consists of contact with not only mental health professionals, but also other people diagnosed with mental illness in several types of associations, such as group therapy and informal peer interaction taking place at different locations. Through this interaction with other people who have severe mental illness, individuals can share experiences, which allows them to situate themselves within this new society. Although each person's background is unique in many way, the sharing of experiences related to mental illness helps a person identify with the plight of the members of a group labeled with mental illness. However, affiliation with the SMI group may be seen as adopting a group of a lower status and may create resentment or avoidance behaviors.

A central category of identity transformation occurred through sharing a common background. Experiences that were seen as unique to having a serious mental illness included the perception that living with mental illness is difficult for those who do not suffer from mental illness and that mental illness can deter others from forming relationships with those with SMI because of the stigma associated with their illness.

The perception of others being unable to understand what it is like to be mentally ill frequently surfaced in discussions with people with SMI. One person described the experience this way:

I just think that most people don't understand it or know what goes along with the side effects when you have depression . . . they don't understand how it really affects your life, how it affects your ability to function, your ability to think, your ability to socialize, your ability to even get homework done, your ability to sleep. It affects me in a lot of ways; most people don't really seem to know about it, so I think it's just been hard . . . I think sometimes you do actually have to feel embarrassment because of your mental illness and you don't want to display that to the world.

Many participants found it difficult to explain the experience to others and often perceived that others did not believe them when it came to how the illness influenced

their ability to function. Many people felt that those with physical problems received compassion and tolerance, but the same gestures were not given them.

Patients reported that the day-treatment center offered them a place where they could be around people who could understand their illness and would not judge them. This type of involvement with others of the mentally ill group provided a refuge from the outside world and allowed patients the opportunity to speak openly about their illness. As one person put it:

It is difficult in the wider world. It is a lot easier to be around people who know I have a mental illness and who understand if I am symptomatic and aren't alarmed by things like that. . . . I think that it is one reason why it feels comfortable being around other people with mental illness because we get the hard times—we know what it is about.

This use of facilities or safe places to openly disclose feelings gives further understanding of the contextual element of identity formation. In examining how psychiatric hospitalization affected identity of inpatients, Jackson, Tudway, Giles, and Smith (2009) identified such places or structures as providing a type of insulation from the norms of society and allowing patients to have their own societal norms as long as they were in the parameters of the structure. Being able to openly discuss one's problems and feeling that they were understood by others appeared to foster a sense of camaraderie.

This camaraderie created by the stigma of mental illness fostered a feeling of togetherness between patients at the day-treatment facility. There appeared to be a natural sense of looking out for one another and accepting each other, even when a person was struggling with his or her symptoms. One said, "I come here a couple of times a week and nobody really has to explain themselves. You are just accepted for who you are." Others identified that having an understanding of mental illness and the discrimination

that comes along with it provided them with a sense of compassion and ability to help others in the same situation. One person who shared this view felt that such service gave him a sense of purpose and well-being: “It makes me feel I belong and I can do something productive. . . I love meeting new people, I can use as many friends as I can get. I’ve had pretty much positive experiences.” This positive well-being that comes from a negative social identity, given a certain context, has been referred to as *identity adaptiveness* (Pittinsky, Shih, & Ambady, 1999). This concept describes a process by which certain contexts can produce positive outcomes from a negative social identity.

Another frequently encountered experience among the subjects of this study was the potential that disclosure of one’s mental illness would have damaging social consequences. Most participants described estrangement and avoidance by friends or family once they find out about the mental illness. Said one:

I have lost a couple friends because of that. . . . I call them up ask, “You want to do something?” “Oh, not really.” I call them up again, and they say, “Oh, dude, I just don’t feel like hanging out anymore.” . . . “Is it something I said?” “No it just doesn’t feel right, it’s not something I really want to do.” . . . When I call them back they say, “Dude, don’t call me anymore.” I had one friend tell me, “I just don’t want to hang out anymore, just don’t call, delete my number off your cell phone, leave me alone.”

Through such experiences, mental illness becomes a condition in which social isolation is embedded as a consequence of its divisive character:

I had a girlfriend, but she found out about the mental illness thing . . . we don’t talk anymore . . . she doesn’t see me anymore . . . it’s because of my “condition,” as she calls it. It’s really hard because you depend on people and all of a sudden they are no longer there to be friends with you . . . and help you and boost you up . . . and you have to find another way to do that within yourself, so I have to be my own friend, I guess.

These common experiences were prevalent in many of the interviews and were described as an intangible aspect of what it means to live with a mental illness. Being able to share these types of experiences facilitates a process through which people of varying backgrounds come together behind the label of mental illness.

### **Group categorization and identity transformation**

The label of mental illness is seen as a symbol by which a dichotomy is created in the form of ill and non-ill groups, with each group of people holding opinions and judgments about the other and acting toward each other based on the viewpoints ascribed to the group. Out of this dichotomy, a dilemma arises for the person with SMI: he can either accept a position in the category of mental illness or to refute belonging to this category. Accepting the label of being mentally ill involves putting oneself into a group that is generally given low social status and defined in negative terms. Denouncing a position in this group may create isolation from others who could offer support and assistance.

The process of acceptance and locating oneself with others within the category of mental illness transforms identity and allows the individual to see himself within society at large. This series of actions helps to define a perspective by which people are able to predict how others are going to act toward them, as well as how they should govern themselves in and out of the mental health world. This perspective does not determine one's entire behavior—it only serves to help the person define the situation that is presented to her, and allows the individual to act according to her definition of the situation. This outlook is therefore seen to shape interaction between one's peers in

mental health treatment as well as those on the outside world who may or may not know anything about such a condition.

### **SMI identity and sensitized interaction**

Subjects described how being a member of a low-status group transformed their identity and created a perspective by which they viewed others. Most subjects in this study acknowledged a tendency to perceive non-ill others as potentially discriminating or looking at their condition in a negative way. One subject identified this sensitivity in relation to how other minorities have to deal with similar issues:

I don't know how to explain it. . . . I guess it is like if you are black and you are hearing black jokes . . . if another black person is telling them then it is okay, but if it's someone of another race it's not okay . . . it's the same thing, you pick up on those things.

The perception that others can be a potential source for bias involves the recognition of stereotypes. Participants readily identified several stereotypes for people with SMI, including being lazy, less capable, unintelligent, crazy, and dangerous. Dealing with these stereotypes becomes another significant task for the person with SMI: "If you tell someone, yeah, I am mentally ill, they immediately think, oh, he is going to kill me; I know a few people who are afraid of me." These stereotypes can be seen as a threat to a positive identity as they create the underlying structures that lead to prejudiced behavior and discriminatory practices.

### **Strategies to deal with identity threat**

Subjects identified several common strategies to lessen the susceptibility to stigmatization by others. While being open and up front about one's mental illness was

spoken of as the ideal attitude, most subjects revealed the need to utilize certain strategies to manage the perceived threat created by exposing one's mental illness.

### Concealing

Concealing the status of mental illness—not allowing others to know about it—is one protective strategy. This strategy included either denying one's illness to others or performing as one who is not mentally ill:

Since I have been dealing with it for so long it is a lot easier to hide and I have always decided that I am one of the best actresses in the world because I can put on a happy face even though inside I may be churning. If I have to, I can act normal for a small amount of time. . . . I haven't been able to work and so when people ask me what I do I always say I am a student, even though I haven't been going to school, so I am the eternal student . . . so I hide it that way . . . or sometimes if people ask me about it, I tell them I have problems with depression. That is my standard answer if they ask about it, but I usually don't share that with people. There are only a few people who really know that I am mentally ill.

Concealing one's illness comes with the risk that eventually others will find out, thus exposing the individual to the consequences. Concealing mental illness can also be seen as a constant source of stress, as one must always be on guard against the constant risk of being found out.

### Limiting disclosure

Similar to concealment, limiting disclosure occurs when an individual informs somebody of his or her mental health disorder under certain conditions; it's a way in which people with SMI negotiate knowledge about their condition to those in the outside world. Disclosure is a process of careful selection, done only after observing and feeling that certain conditions have been met. The person has to feel comfortable with the individual to whom he or she is disclosing, and the comfort occurs when other

conditions—such as trust, compassion, and understanding—are seen over a period of time. One patient described it this way:

You don't tell people really, because they look at you differently or they'll put a stereotype on you. . . . I just think you have to know who you're talking to, because sometimes you don't want to talk to them about something that will just cause them to treat you differently. . . . I think it also depends on the impact of your drop, like if it's somebody that's prestigious, somebody that's going to be able to give you a job . . . or say we're not going to give you a job because you have a mental illness, I think you have to be selective of who you tell for that reason . . . [I tell] people that are close to me, people that notice that I'm acting different or that are in a close enough relationship with me that I feel comfortable telling them and that they're going to be able to help me through it or . . . if they're somebody important in my life, then yeah, but what's the purpose of telling them if it's not really going to impact anything?

Disclosure of mental illness was often described as being most difficult in the beginning of the mental health treatment experience, but as becoming easier over time and through a process of self-acceptance, as described by this individual, who has been in treatment for schizophrenia for a considerable time:

When I was younger I was going to the old clubhouse down at [the mental health center] in the basement. I didn't want anybody to know hardly at all that I was going down there, except for the people that were down there. I was going to [college] up here, and I did not want any of the people up there to know that I was down there in the daytime, so I was very, very cautious. I wouldn't go bowling with them at the [college] bowling alley they used to have. I wouldn't go out on errands unless I knew some of the other people wouldn't see me there. Now I'm still somewhat cautious, still confidential, but if somebody finds out it doesn't bother me as much as it used to. . . . I've passed that stage in a lot of ways because I've been in the system now for 31 years. When you're in it that long you get to the point where it doesn't matter as much what people think. For instance, we had a garage sale here and I just sat right outside the building and watched all the stuff, the cars were going by and it didn't matter to me really that much that they saw me as having mental problems. Even one guy stopped and I knew him from a previous church I was in, it didn't matter that much to me that he saw me sitting in front of this building that we're in, so I'm getting to the point now where it just isn't such a big deal.

This person's account of disclosure can be compared to that of another participant, a younger man with less experience being mentally ill:

I don't talk to people about being schizophrenic because I think it scares people away. I think that people look at me weird . . . or they look at me like I was something to be gentle with. . . . I go to school up here and nobody knows. The only people that know are my mom and my sister and my dad and my family . . . or people that have had experiences with me in places like this.

These descriptions demonstrate not only the process of limited disclosure as a strategy to manage one's identity, but also how this strategy may change over time and with experience. This concept of selective disclosure has been found in other studies to optimize social support and limit stigmatization (Bos, Kanner, Muris, Jannssen, & Mayer, 2009).

#### Maintaining physical appearance

Another strategy that people in this study found helpful in limiting stigmatizing behaviors was maintaining physical appearance; they present themselves to the world as normal as they can appear physically. For the person with SMI, physical appearance takes on added importance, as this may be one of the ways they can reduce the risk of being stereotyped. One person said this about maintaining physical appearance:

It is important to be clean and showered and wearing fresh clothes and things like that when you are going out into the wider world . . . there's a connection between how crazy people think you are [and] how stinky you happen to be.

The act of maintaining physical appearance was spoken of by only a few participants in this study—and they were the ones who dressed well and appeared to have an awareness of the impact of physical appearance. Many other subjects did not acknowledge physical appearance as a means by which a person's identity may be threatened. In fact, one



subject discussed letting go of his physical appearance as part of the transformation to his “new me”:

I used to gel my hair, [but] all these things that were important to me became not important. . . . I set down a lot of things of personal care requirements that you would usually do. I mean, I still take showers and stuff like that but I am [worried] about all that impressive stuff that people like to do to themselves. . . . I don’t feel it is important, I don’t feel it helps me to be peaceful.

Judging others as worse off

The final strategy among study subjects was the inclination to compare themselves to other members of the treatment group. Members would informally discuss individuals who seemed worse off than themselves in their abilities to care for themselves, their financial status, the number of medications that they took, and the number of times they had been hospitalized. By making comparisons, people seemed to create a hierarchy whereby they increased their own sense of value by being better off than other members at the treatment center. The ability to compare favorably to others demonstrates the heterogeneity that exists within the community of people who are identified as serious mentally ill.

The need to maintain a positive identity, even as a member of a symbolically devalued group, is seen as a primary directive that incorporates all of one’s interactions. This need remains important, even in situations where strategies to manage identity threat may be reduced or eliminated, such as in healthcare interaction.

### **Healthcare and the identity of serious mental illness**

Healthcare can be seen as a process of interactions between an individual who is recognized as the patient and individuals who are recognized as healthcare providers.

Each of these providers has a certain expertise obtained through education and training, as well as his or her own experiences that have shaped how he or she thinks about situations, people, and experiences. Patients also bring experience from the past and goals for the interaction. They approach the interaction trying to accomplish these goals based on their ability to interpret the situation and strategize to obtain their desired results.

Healthcare interaction can present a dilemma for the person with serious mental illness in relation to maintaining a positive identity. The healthcare process is seen as an interaction between members of the ill and non-ill groups, so interaction is susceptible to all the stigmatizing practices seen in society at large. This interaction is also seen as unique because disclosure of all relevant conditions is required, which eliminates many of the strategies used by people with SMI to keep their illness hidden and to maintain a positive sense of identity.

Participating in healthcare involves several potential interactions with many different people as part of the process. Subjects generally focused on their medical providers when describing interactions, although interactions with other members of the healthcare team were explored. Many subjects perceived medical providers as less likely to stigmatize based on their assumed knowledge of mental illness, their position in a field that acts to help others regardless of circumstance, and their overall position in society.

One subject said:

I feel safe with doctors. I think they are there to treat me or take care of me so I think they deserve to know something that may be in the way. . . . I think it's a profession that cares. . . . I can open up to them because I feel that they care.

Others felt that medical providers were as susceptible to the stigmatizing beliefs about mental illness as others in society: "Some understand it but others just kind of put you in

a pigeonhole as a mental case and let the psychiatrist take care of that.” The different beliefs appeared related to past experiences that had shaped the person’s perception about medical providers. Although many individuals seemed to have had at least one difficult encounter with a medical provider, most of them could also describe having positive relationships with current or past providers.

Disclosure of one’s mental disorder was seen as necessary because of the understanding that either one’s mental illness or the medications being taken for it could somehow interfere with the treatment prescribed by a person’s medical provider. Either by having their diagnosis established in the record or by telling about their medications, they needed to disclose their mental illness:

I can’t hide that, I wish I could sometimes . . . they find out . . . even if you’re not wanting to really go into your psych history, they are going through your prescriptions so they ask you what you’re taking it for, so they find out that way, or they automatically know because they recognize the medicine as a psych med.

Some individuals took a more passive approach in reporting their mental illness by filling out questionnaires or mentioning it in passing. Often the mental illness was not seen as important for the interaction and therefore was not mentioned: “I didn’t tell them, not for confidentiality, but because I don’t know if telling them would have helped me with my medical condition.” Another patient related the following attitude about disclosing: “If it comes up I will tell them about it; if it doesn’t, why bother? They are not treating me for that, they are treating my medical problems.”

Others recognized the connection between their mental health and their physical health. By taking such a stance they could cultivate a greater transparency and thus improve their outcome: “They can’t treat my body if they don’t know what is going on in

my mind. My mind and my depression are just as important as treating my body.”

Although several patients acknowledged the connection between mind and body, few patients actually wanted to discuss their mental health problems with their medical providers because they felt they would be treated differently, that the mental illness would distract the medical provider, and that they would be treated as incompetent or drug-seeking.

### **Being treated differently**

The most common reason for not wanting to discuss mental illness at a medical visit was fear of being treated differently once the mental illness issue came to light:

I am sure I didn't say it right at the beginning because then it is all about [that] instead of having a real problem . . . they always think it is because you are stressed or depressed and not that you could have a real medical issue going on.

The stigma of mental illness promotes prejudiced opinions and discriminating behavior toward people with SMI among the general population, and it was seen as having this type of destructive influence in healthcare interaction as well. Serious mental illness was felt to discredit the authenticity of symptoms:

I have noticed being treated differently . . . if they're having a hard time figuring out what's wrong with me, if they recognize or see that I'm on psych meds and know that I have an emotional problem they'll automatically just default to [an emotional problem], not a physical one

The process by which physical symptoms are misattributed to a mental illness has been described in the literature and labeled as *diagnostic overshadowing* (Jones, Howard, & Thornicraft, 2008). Diagnostic overshadowing was seen as invalidating and difficult for many patients to accept:

You swallow your pride and you take it and you accept being treated like a child and being treated like less of a person because you need the help. You need what help they can give you if they can give you any. It makes me feel like I am less important than maybe their other patients because [my problem] is supposedly in my mind.

This type of interaction creates a sense of mistrust in the medical system and was cited as a reason to forgo further interaction by one patient who had a difficult interaction after being told that one of her medical illnesses was caused by stopping her psychotropic medications: “So have I gone back to another office visit with him? I avoid him completely, I won’t, I don’t ever want to go to him, so I just go and get my IV treatments. . . . I’m hoping for more options.” The concept that SMI is a condition that leaves a person vulnerable to being treated differently in the context of healthcare supports the identity of mental illness as a sensitizing construct that can change interaction. Defining mental illness identity as a potential threat to receiving different or substandard medical care demonstrates how powerful this identity can be, not just for the medical provider, but also for the person seeking care.

### **Mental illness as a distraction**

Participants described other types of problematic encounters with medical providers, such as when the visit becomes overly focused on their mental illness and not centered on the reason for making the appointment:

I have to make sure it doesn’t become too much of a diversion in the visit. For example, if I’m there for a migraine or if I’m there for colitis or something else, [the mental illness is] part of the mix, but it doesn’t need to be the entire focus of the visit, so, that’s been something I’ve tried to juggle.

Serious mental illness has the capacity to be the predominant way of viewing a person because of its distinguishing characteristics and way in which it stands out. This

viewpoint can therefore capture the attention and leave less dominant issues to be dismissed or forgotten about. This leaves the person with SMI the need to maintain focus on the reason for the visit.

I try to keep it separate from the physical conditions because if I focus on that too much they tend to focus on it more and I want to get the physical part fixed. I already have a doctor for my mental conditions so I want to concentrate on the physical part, which is separate

Subjects identified their mental illness as having such a dynamic influence on their interactions with medical providers that it overshadowed other possible problems that they were having. “They forget. I think, that a person with a mental health issue could also have a real physical health issue at the same time.” The ability of one’s mental illness to become the predominant way they are viewed creates the situation where it may eclipse other problems.

### **Stereotyped as less competent**

In addition to the distracting nature of SMI, dealing with stereotypes also becomes part of the challenge in the healthcare interaction. Several stereotypes were described by participants; a common one was the stereotype of being less competent or unable to understand and comprehend one’s situation. Such stereotyping created frustration, as explained by this individual:

I felt like he put me under a microscope because I had psychological issues, like I shouldn’t be able to psychologically handle a lot of the stuff we were dealing with or I didn’t have the mental faculties to understand what he was discussing. He’d try to discuss my back, because I had issues with a disk. He would say, “I’m trying to tell you this, but I don’t know if you’ll understand it,” so he was trying to simplify it. I asked him one day, “Can you just tell how me you would tell a normal patient?” and he said, “I don’t think you would understand it like the rest of my patients.” That really offended me, that he didn’t think I could handle the medical explanation of it . . . it’s not like I can’t understand what people talk about

or anything, it was just that I had some other issues that made it to where I had other problems, but all my faculties were there, my ability to understand and comprehend medical terminology was still there, but I got treated like I was not a hundred percent able to understand things or deal with it or he was afraid to tell me what he needed to do in order to fix my back. . . it was annoying.

Several people interviewed for this study recognized being treated differently in a way that made them feel less capable of understanding or being able to deal with normal health interaction dialogue. As one patient put it:

It's uncomfortable, you feel like your chart's red-flagged . . . like "this is the nut case," or rather than just being a more complicated patient that they're straightforward with, sometimes they are so deliberately extra careful, that walking on eggshell thing. . . . I want to tell them, just relax, it's okay, I can be a normal patient. A lot of times they overdo it with the gentleness or being super careful, or like when you meet someone who doesn't speak English and you start talking as if they were a child or stupid or something, it's the same kind of thing.

Relating to people based on stereotype rather than on individual characteristics can be an affront to one's identity and can promote dissatisfaction with the healthcare process.

Interactions like this also reinforce the self-stigmatizing properties of mental illness as patients must now look at themselves from the point of view of the healthcare provider and incorporate this understanding of themselves into their socially constructed identity.

This type of interaction can be particularly difficult for people with serious mental illness, as healthcare providers were often expected to have a better understanding of mental illness than the general public by most of the patients in this study. As one patient described her experience with her primary care physician:

It seemed she felt overwhelmed; in fact, I've had medical doctors tell me that they're overwhelmed with it and they refer me out . . . but she had me go check myself into the hospital when I was just talking about my depression, because she got overwhelmed with the strength of the emotions of depression, when I didn't really need to be hospitalized . . . when she got overwhelmed with the emotions and wasn't sure . . . she was

worried I wasn't safe . . . [The experience] made me scared, because if they're feeling overwhelmed with me, what am I going to do?

Disagreement with stereotyping practices is articulated as a common concern among people with SMI in this sample because of the potential for acts of discrimination and unfair treatment.

### **Drug seeking**

Another stereotype faced by people with SMI is that of drug abuse. Many patients cited problems with pain-related issues, and several felt that because of their mental illness, they would be singled out as seeking pain medications that were not justified:

I had trouble with one guy who pulled my wisdom teeth. It went really badly, maybe because I'm so old—I didn't have them done until my late 40s and they had huge roots—but I really had trouble with pain control, and he was treating me like I just wanted drugs. Finally I just laughed and said “You know, there are lots easier ways to come up with drugs than to have some guy take your wisdom teeth out.”

### **Strategies for healthcare interaction**

People with serious mental illness are known to have poor follow-up with medical care (Salsberry et al., 2005). One of the reasons cited by individuals in this study for a delay in initiating medical care was related to the perceived need to hold out until symptoms became so obvious that they couldn't be ignored: “I do physicals and stuff when I have to but . . . I usually wait until it was obvious that I was sick and not faking it or being emotional.”

The need to be able to demonstrate obvious symptoms shows what a symbolic barrier mental illness can be in healthcare. As a discrediting condition, serious mental



illness has the ability to undermine authentic complaints related to medical problems and assign causality to a psychological phenomenon through an attributional process.

### **Seeking out providers who understand**

Another strategy people with SMI frequently cited was the need to seek out medical providers they felt understood them and would not stigmatize them. In some cases medical providers with the reputation of being accepting and helpful were shared among the subjects through word-of-mouth referrals:

I have some experience with physicians and how they vary and I've had to search, I've had to hunt, to come up with the ones that have the intelligence and the perspective to sift through this, so it's not an either/or situation, but that this is a whole person with a variety of issues, among them are mental health issues, so its been a challenge. Right now I'm happy with where I'm at, but I have to be willing to change or keep looking.

In contrast to the practices that appear to thwart positive healthcare interaction, participants identified several providers who facilitated healthcare activity and were viewed as positive in terms of acceptance, respect, and ability to empathize.

### **Facilitators of healthcare for people with SMI**

Acceptance of a person's mental illness by a healthcare provider allows patients to openly discuss their mental illness without being subjected to the negativity they are accustomed to when revealing their condition to others. Through these experiences, patients begin to value healthcare interactions:

He's probably the one that has made it easy and has accepted the depression and knows what it is. He understands that you need the meds but it is also part of the whole body and it is part of the whole healing process.

Acceptance was seen as one of the most sought-after qualities of good medical providers.

This quality facilitated interaction and helped people with SMI feel valued:

The ones who have been more positive for me accept the mental illness as an illness, as . . . a brain abnormality . . . and they accept that it has its side effects and they will treat the side effects, despite having the mental condition. They don't talk about it. They talk about what is at hand.

Willingness to spend time and treat the person in a respectful manner made people feel valued:

His manner has always been very straightforward and friendly. At every visit no matter what I am seeing him for he always asks if there is anything else that might be going on that he might need to check and takes the time to check it if there is. I never feel rushed even though I know he is budgeted only a certain amount of time. I never feel like he is rushing me out of the office or anything like that.

Finally, the ability to empathize was regarded as a valued quality among healthcare providers:

You can tell the ones that really get it, because they're more empathetic, they really know what you're going through and are sorry you have to go through all this, where the other ones, they almost get annoyed that you're there, that they have to deal with you. They'd rather deal with just the strictly medical problems, instead of emotional problems.

While an abundance of negative experiences with healthcare providers prevailed in the accounts given by participants of this study, these helpful qualities were recognized as sources that promoted participation in healthcare activity and ongoing wellness.

## **Discussion**

Serious mental illness as a socially understood principle is theorized to create an identity for the person that acts to define and change interactions in the healthcare setting. Through internalizing the socially understood meaning of mental illness, a person's view of himself and how others view him changes after a diagnosis of mental illness is made

and accepted. This label creates a new way to view oneself and to understand how others may view one once the condition becomes known. Because of the stereotypes of mental illness that exist in society and are passed along through interaction with others, mental illness becomes a condition that changes identity as well as transforms interaction with others, including medical professionals. These findings are supported by the themes of mental illness as “a transformative identity construct” as well as a “transformative identity in healthcare interaction.”

Serious mental illness as a transformative identity construct describes how having a mental disorder acts to change identity from both an internal perspective as well as from the perspective of others. Subjects in this study identified having knowledge of common stereotypes held by society and often felt the same way before they were diagnosed or had treatment for their mental disorder. The initial contact with mental health treatment becomes a crucial time, as the diagnosis ascribed to their condition now creates a challenge to incorporate beliefs about mental illness into a view of one's self. As part of the transformed identity, an awareness and understanding of how negative stereotypes influence interaction with others takes place and strategies to deal with limiting the negative influences are employed.

The transformed identity of a person who suffers from SMI also can influence healthcare interaction. Subjects in this study described changes in the way others viewed them and interacted with them once their mental illness became known. This perception of how a mentally ill identity changed interaction was also felt to occur with medical providers as well. People with SMI described strategies to avoid healthcare contact until

symptoms became obvious or to change medical providers until they found one that was empathetic and able to facilitate positive healthcare interactions.

This study was limited in its scope by a number of factors. Participants for this study were recruited from a community mental health day-treatment facility, so all subjects had some degree of acceptance of their disorders and need for treatment. The results of this study reflect only people who are willing to acknowledge some aspect of their identity as mentally ill. Nevertheless, most participants cited having attempted to deny their mental illness, especially in the beginning of their treatment or at other periods of time in which they rejected treatment and the identity that came along with it.

The data for this study was collected from one community mental health center located in a rural city, which may limit the generalization of results into other areas. This study is also limited by looking at only what subjects recalled as their experience and not direct observation of what may have occurred in the context of actual interactions, which could have been shaped by many different forces occurring under a variety of circumstances.

This study was conducted using grounded theory, a qualitative methodology, and therefore is limited to provide explanation only for the population being studied. Future work will have to be conducted before further generalizations can be made.

This study also has a limited scope of investigation into healthcare as a social process. While many factors contribute to the difficulties that people with SMI may experience through their encounters with medical providers, the aim of this study was to look at healthcare as a social process that can be deconstructed and understood through the symbolic nature with which society interacts. While the impact of such understanding

is significant, it can in no way fully explain all the intricacies of the problems encountered in healthcare interaction.

This study was conducted to increase understanding of how the stigma of mental illness shapes the process of healthcare for people with an SMI by looking at how being identified as a person with mental illness shapes the framework for healthcare interaction. The implications of this study act to inform healthcare providers of the potential problems faced by people with serious mental illness when addressing their healthcare needs.

## CHAPTER 4

### THE EMERGENCY ROOM NURSE AND SERIOUS MENTAL ILLNESS

#### **Introduction**

Interfacing with the healthcare system is often difficult for people with SMI and has therefore been surmised as one reason why this population has such poor health outcomes (Druss, 2007). Many deficiencies are seen when looking into the factors that influence quality healthcare, including having reliable transportation to make it to appointments and the financial resources to pay for treatment (Dickerson et al., 2003), being able to recognize and discuss medical problems (Goldman, 1999; Phelan et al., 2001), and having the ability to navigate through a fragmented healthcare system (Horvitz-Lennon, Kilbourne, & Pincus, 2006) that often has poor communication and coordination between providers in psychiatry and medical care (Druss, 2007). As a result of these influences, people with SMI have demonstrated lower rates of utilizing preventive care (Druss et al., 2002; Salsberry et al., 2005), higher rates of emergency room care (Hackman et al., 2006), and more frequent hospitalization due to ambulatory care-sensitive medical conditions compared to the general population (Li et al., 2008).

The stigma associated with mental illness has also been suggested as a reason people with SMI have difficulty obtaining quality healthcare. Stigma is defined as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 3). Attributions made about the

cause and controllability of a person's illness lead to inferences about the responsibility that person has for his or her condition. These inferences cause emotional reactions, which result in purposeful behavior such as discrimination or avoidance (Weiner, 1995).

Although people working in healthcare are expected to have an open-minded view of people with mental health problems, stigmatized views of people with mental illness have been shown to be prevalent among healthcare workers. For example, 108 healthcare professionals completed a survey regarding a fictional person with mental illness; participants had high stigmatizing attitudes toward those suffering from schizophrenia (Rao et al., 2009). Bjorkman, Angelman, and Jonsson (2008) found from a questionnaire that nursing staff in somatic care perceived people with schizophrenia as unpredictable and dangerous. Medical providers have also been shown to be less likely to believe the physical complaints of people with SMI compared to people without mental illness (Graber et al., 2000; Jones et al., 2008; McDonald et al., 2003).

People with SMI frequently encounter primary care providers who do not feel comfortable treating mental illness (Lester et al., 2005) and psychiatric providers who have not been trained to address physical health issues (Vreeland, 2007). Even when people with SMI have access to medical care and make frequent contact with medical providers, the overall quality of care they receive is substandard (Miller, Druss, Dombrowski, & Rosenheck, 2003) and less satisfying compared to the experience of people without mental illness (Kilbourne et al., 2006). With such difficulty accessing quality medical care, people with SMI are prone to overuse emergency rooms as medical points of care (Merrick et al., 2010), where they encounter providers who have limited expertise working with people who have SMI outside of crisis situations.

Emergency room departments function to provide treatment for acute illness and traumatic injury that strike unexpectedly (Derlet, Richards, & Kravitz, 2000). Because of overall decreasing emergency rooms and increased emergency room visits (Garcia, Bernstein, & Bush, 2010), emergency departments face increasing pressures related to overcrowding (Schull, Slaughter, & Redelmeier, 2002), which can affect the ability to provide dependable and rapid emergency care (Lynn & Kellerman, 1991). Additionally, emergency rooms have also become the principal suppliers of non-urgent primary care to the underinsured or noninsured (Jackson, 2001). These factors—as well as staffing shortages, lower rates of reimbursement, and treatment of sicker patients—have created serious challenges to many emergency room departments (Carpenter, 2001). The pressures created by such challenges faced in the emergency room can create problems for both staff and patients.

One potential problem faced by people with SMI is the requirement to interact with medical providers who may be uncomfortable working with them. Unfortunately, little is known about how providers working in medical care without a psychiatric specialty view people with serious mental illness and how these views are formed and maintained. Therefore, this study examines the beliefs that nurses working in an emergency room have in relation to people with serious mental illness and how those beliefs frame interaction in a healthcare setting.

## **Methods**

This is a qualitative investigation into how the stigma of mental illness shapes healthcare interaction in an emergency room (ER) setting between nurses and people with serious mental illness. Qualitative research is ideal to study this problem as it is a way to



gain insight by discovering meanings of experiences and improving understanding of the whole (Burns & Grove, 2001). Exploring this subject with a qualitative methodology allows for careful investigation into the beliefs that lie beneath social behavior and act to increase understanding of this problem. As explained, this study uses a symbolic interactionist perspective to guide the methodology.

### Participants

Subjects for this study were obtained through the University of Utah and its hospital system, from which nurses were recruited. All subjects consented to involvement in this study consistent with the practices outlined by the respective institutional review boards.

Nurses were recruited for this study from a busy ER in an urban hospital serving a population located along Utah's Wasatch Front. Nurses were recruited from the ER because they frequently have contact with people who have a serious mental illness but they do not have special training in treating mental illness. Recruitment for this study was done with a flyer explaining the study parameters and asking interested individuals to contact the investigator via telephone or email. To participate in the study, nurses had to have at least 1 year of employment as a nurse in the ER. Participants also had to agree to be interviewed and audio recorded. Denial of consent to interview was the only exclusion criteria. Subjects were given a \$25 gift card to a local store for taking part in the study.

Participants in this study included 7 women and 1 man with ER nursing experience ranging from 1 to 15 years. All participants had other nursing employment prior to working in the ER, and several nurses had other concurrent employment outside

of the emergency department. No participants reported having had prior work experience in a behavioral health department.

### Data collection

Data for this study were obtained by interviews conducted with eight nurses working in an ER. The nurses were interviewed individually using an open-ended format that asked them to describe their experiences working in the ER and their involvement with people who have serious mental illness (see Appendix B for sample questions). Questions focused on the structures that facilitated the way ER nurses interact with people who have SMI and the process of how they learned to view this population of patients. Initial interviews helped define the context of the issue, and later interviews were used to clarify and gain further understanding of the issues.

The interviews were conducted in the hospital where the nurses were employed in a designated room that was allocated by the facility. All interviews were audio recorded after consent was given. The same procedure was followed with the nurses as with the mentally ill subjects.

### Data analysis

The research methods of grounded theory (Strauss & Corbin, 1998) were used in gathering data from the nurses, as it was with the mentally ill subjects. The same software package for qualitative research analysis was used, and the same processes of transcription occurred.

## Results

The general finding of this study is that serious mental illness has a pervasive detrimental influence on interaction for healthcare providers as exemplified by nurses working in an ER. This finding was supported by the themes of role incongruence, identity overshadowing, and segregational sensitivity.

The theme of role incongruence postulates that mental illness acts to create an identity for the patient presenting with SMI, and this identity in turn serves as a disconnect between what ER nurses value in their roles and what they are required to do with this population. The identity and perceived role of an ER nurse is one who has the ability and skill set to provide care for the most critically ill or injured of patients. Patients presenting for psychiatric emergency are seen as different from other types of patients.

The second theme of overshadowing identity refers to the ability of mental illness to create a dominant discourse of how people with mental illness are viewed and thought of. This theme addresses the way in which serious mental illness is meaningful to the ER nurse as a concept to describe aberrant behavior in the emergency room that may or may not be related to mental illness and how other discourses of mental illness are difficult to recognize.

The third theme supporting the general finding is the theme of segregational sensitivity. This theme argues that mental illness as a construct is associated with a system of beliefs that segregate this patient population and create a sensitizing framework for interaction. Through exposure to patients exhibiting acute and severe symptoms of mental illness and a process of internalizing the beliefs of their peers, ER nurses develop

a system of looking at patients with SMI as more difficult to understand, dangerous, frustrating, and often time-consuming compared to other types of ER patients. These beliefs act to change interactions with people who have a mental illness and create a context for interaction where nurses distance themselves from patients with SMI.

### **Identity of an emergency room nurse**

Identity refers to the process of self-conceptualization that allows people to see themselves as objects and be able to categorize, classify, or name themselves in particular ways in relation to other social categories or classifications (Stets & Burke, 2000).

Identity develops out of belonging to a group or having a role that facilitates a sense of one's place in society or the situation in which social interaction occurs. This sense of self shapes interaction by delineating one's role given a particular situation and how one acts to define the situation. ER nurses in this study described having an identity that developed by means of skill acquisition, role formation, and a process of socialization. This identity formed a basis by which they viewed patients: based on their need of perceived ER nursing skills and role without having psychiatric specialty.

Nurses interviewed for this study described becoming an ER nurse as a process that started through education and training in basic nursing education. Nursing education and subsequent licensure led participants into entry-level opportunities in different areas of nursing employment. All nurses interviewed for this study held jobs in various areas of nursing before coming to the ER. These opportunities afforded them the chance to gain basic knowledge and skills in preparation for the ER, but it was explained that “nothing you've seen before is like the ER.”

For the participants, the ER symbolizes a place that can provide for a wide range of problems requiring an equally high amount of expertise and skill. Subsequently, working in the ER requires acquisition of new knowledge and skills. Gaining these abilities and becoming proficient was seen as a high priority by the less-experienced nurses, and something that came through familiarity over time. As one put it:

By taking the patient and asking questions and having to, you have to do it, and if you are given an order and you don't know what it is you have resources to look it up and then you go do it and then you will always remember it. When I do it, I always remember it . . . on the job, that's the only way you can learn. You have to be there to do it, to learn it.

Even with the acquisition of new skills, abilities, and experience in the ER, being an ER nurse requires a level of expertise and comfort to be able to manage difficult situations. Speaking of her experience before she felt she could identify herself as an ER nurse, one participant stated:

It takes a couple of years at least of being here, because for a long time you are very uncomfortable every time you come to work because you're just not sure you are going to do the right thing at the right time for the right person and know what to do in that situation. It probably took a couple of years and having a few experiences that go well to think we can really do something for somebody and really make a difference.

Having confidence in skills and abilities is seen as important in the ER by nurses who identified the need to be able to deal with highly critical situations. Being able to participate in these types of cases was viewed as the most important aspect of ER nursing and for most provided a sense of satisfaction:

When someone comes in with a crazy [heart] rhythm and you are doing CPR and all of a sudden you give them medication that puts their heart back or if you are able to shock them back into regular rhythm, it is amazing. That's probably my favorite thing.

Although most of the ER nurses interviewed for this study discussed satisfaction from participating in cases of the most critical nature, they also acknowledged that most of their time is spent caring for illnesses of a chronic nature:

As an emergency room nurse, what we deal with more than half of the time is not an emergency . . . of course it is not the stuff that is fun for us . . . people that enjoy emergency medicine like having to help someone that actually has a life-threatening problem going on, so that is what I consider emergency medicine—someone coming in with a life-threatening problem.

This ability of the ER nurse to participate in the most critical situations becomes a valued part of the ER nurse's identity and helps to explain the way these nurses perceive working on other, less serious cases. As most participants explained, less critical cases are seen as more mundane and are given less attention:

It's about prioritizing and making sure the person that needs you the most, you are there for and then you work down and that might be part of the reason why part of the mentally unstable patients get ignored a little bit because that is not as much priority at the time.

Consequently, study participants appeared to have less appreciation for the conditions and cases that required little use of the skills valued by ER nurses. Caring for patients presenting with a medical emergency was seen as requiring high levels of ER nursing intervention, whereas caring for someone with a psychiatric emergency was seen as much different and reflected the value placed on being able to use critical care skills. As one nurse described:

You know there is not a lot you are going to be doing, you know, intervention wise, you are not going to be usually starting an IV, maybe you give one med, get a box lunch for them or something like that, but there is not a lot that we are going to be doing.

The value placed on being able to utilize what is seen as a distinct set of ER nurse skills figured into the conceptualization of what all participants in this study recognized as the

identity associated with being an ER nurse. One significant category that emerged in response to this value judgment was the general inability to value working with people presenting with psychiatric illness.

### ER nurses are not psych nurses

ER nurses distinguished themselves as *not* having a specialty in mental health nursing. When inquired about their level of comfort and level of expertise working with people with SMI, the nurses responses, “There is a reason I did not go into psych,” or “We are not psych nurses.” This common disclaimer appears as one aspect of how many ER nurses view themselves, which was exemplified by one nurse:

There’s a reason we are not psych nurses. Me, I couldn’t do it. I think most of [the ER nurses] feel the same way I do because we’ve talked about this, a few of us. The ones who need help, I will do anything to help them, and I think that is the same with most of us on the floor. The ones that are here just abusing the system . . . it gets tiresome, and I think that is a general consensus.

To assume the identity “we are not psych nurses” allows the individual to limit his or her role in providing care behaviors and to distance him or herself from responsibility for this population of patients. Whereas nurses may see themselves as major contributors in taking care of critically ill patients, their identity allows them to take a less active stance when dealing with a person with SMI and leave the responsibility to people who identify more strongly with this role. This provision also creates the circumstance where people presenting with psychiatric illness are looked upon as not fitting with the general population of ER patients because they don’t need medical intervention:

I think as a whole, not just my perception, ER nurses tend to look at somebody with a mental illness probably on a lower level . . . they don’t want to take care of that person because they are coming in with mental issues. That is how I see it from my standpoint, unfortunately.

The poor fit that ER nurses perceived that patients with a serious mental illness presenting in the emergency room have with the perceived role and identity of emergency room nurses sets up an underlying structure for interaction. This structure reflects an overall view that the skills that ER nurses value the most are not suitable to intervene with this patient type and therefore the responsibility is designated as not theirs. With ER nurses assuming this stance, the perceived need for interaction becomes limited as this type of case is seen as a lower priority requiring little ER nursing intervention.

When ER nurses had experiences that changed the context of their exposure to people who were mentally ill, they recalled having a change in their perception toward them. One nurse described how having a family member deal with a mental illness fostered change in her outlook toward people with SMI:

I had some personal experiences dealing with some close family members . . . and it changed for me—this is somebody’s dad, this is somebody’s brother. They have a family, somebody loves them, they are doing this, they are not choosing to be this way, they truly are sick. Like depression and stuff like that, there truly is a mental illness. Like it really is something, it’s just not they are crazy making it up or whatever. There truly is. You can treat it almost like a cancer, really in my mind now.

Changing roles between ER nurse and concerned family member of someone dealing with a mental illness provided a different perspective from which this nurse was able to define future contacts with this population of patients. Another nurse identified how seeing people with SMI function in the community allowed her to look at them as ordinary people, functioning with multiple roles, similar to most other people:

I think that we sometimes forget that they, well some of them, are living and trying to live a functional life, so I will see them out in a functioning society and then I will see them here and you forget that these people go back to a place where they are a mom, or a professional. I think that sometimes you just don’t see it as two separate things. You think, “Oh, this person is psychotic,” but really, I think, seeing them in a functioning



atmosphere has helped me realize that this person has psychotic episodes and you can still be psychotic and functioning. . . . I think we don't give them enough respect, because sometimes, I don't know how they do it.

The participants who acknowledged experiences that challenged their beliefs about people with SMI found them outside the ER and outside their role as ER nurse. Being able to change the context in how these nurses were able to make contact with people who have mental illness also allowed them to see beyond the identity of SMI into such roles as family member or community member, which appeared to create a change in how they perceived such individuals. This change of perception about people with mental illness supports the supposition that the role of ER nurse and the identity that comes with it acts to create a belief system of how to view people with SMI. Stepping out of the role of ER nurse and into that of family member or community contact changes the beliefs and perceptions about people with mental illness.

### **Overshadowing identity of serious mental illness**

In its most symptomatic presentation, mental illness creates a dominant concept of how it is viewed by participant ER nurses as related to the type of thoughts and behaviors seen by people who are presenting for psychiatric emergency. These different behaviors prompting psychiatric emergencies are generally out of the norm for socially accepted behavior, and many times is quite dramatic. The impact of seeing such expressions of mental illness leaves a long-lasting impression and serves as a point of reference from which to identify serious mental illness, while leaving other presentations of mental illness less recognizable. For example, in this study ER nurses were asked to describe interactions for patients with SMI presenting with medical problems. Most nurses found it difficult to describe having interactions with SMI patients unless they were being seen

for psychiatric emergencies. When ER nurses were asked to discuss problems they had working with SMI patients, they reverted back to patients presenting for psychiatric emergencies rather than SMI patients presenting for medical problems.

This dominant conceptual viewpoint of mental illness may become the lens through which ER nurses relate to SMI. Other presentations with aberrations in behavior related to substance abuse, cognitive disorders, or other such conditions may be seen to fall under this umbrella because of their similar presentations as socially unacceptable behavior and their required level of intervention.

While such presentations may be unrelated to serious mental illness, they are often viewed within the same framework as serious mental illness because of the conceptual basis of serious mental illness. Conversely, other presentations of mental illness—such as the stable patient with SMI who presents asymptomatic with a medical problem—may not be considered as mental illness because such patients do not fit in the schema of seriously mentally ill.

Serious mental illness characterized by dramatic symptoms and behavior was also prominent as ER nurses described their pre-ER nursing experiences with the SMI patient. SMI was not recognized often when describing employment experiences prior to working in the ER. Due to the limited display of behavior associated with mental illness in other areas where they had worked, nurses had difficulty recounting interactions. While participants recognized that they may have provided care to people with a mental illness during their pre-ER nursing experiences, it was often something that did not get much attention:

It was never the reason they were admitted, it was always a secondary diagnosis or one of their multiple diagnoses. I think unless you had an

actual episode I don't think it was something you necessarily focused on unless they had an episode where they had attempted to do something or to harm themselves or they became combative or acted out, it wasn't something you thought much about.

This tendency to be unaware of a person's mental illness until the unusual behaviors associated with it are seen and the mental illness takes a more prominent role is related to the concept of *identity salience*. This concept, described by Tajfel et al. (1971) as part of social identity theory, hypothesizes that people have many different identities that become salient depending on the context in which the person is in at the time. Therefore if a nurse is charged with the duty of providing care for some type of physical injury or illness of a mentally ill person while on a medical floor, the identity of mental illness may be of low importance compared to the identity of a person with an abdominal injury or cardiovascular disease. However, if this same patient begins to exhibit symptoms of mental illness, the identity of being mentally ill may become much more salient in the way that the nurse approaches this patient and what care is given.

Since nurses working on general medical floors or other similar locations may rarely observe patients with SMI symptoms, the identity of a mentally ill person may be of low importance. However, nurses working in the ER described seeing acts of aggression, psychosis, or other disturbing behavior on a frequent basis and becoming sensitized to the potential problems that may come up when caring for someone with mental illness. The encounters with people who are mentally ill during times of crisis are so remarkable that they seem to overshadow most other interactions and create a situation where this aspect of mental illness becomes the predominant way of seeing mental illness.

Having this conceptual picture of SMI also leads nurses to some frustration when dealing with SMI patients. As one nurse reported, frustration often comes from the perspective that “we don’t see them when they are doing well”; often the only view of mental illness they have is the symptomatic expression of it, and they rarely see people with SMI functioning without symptoms. This overshadowed identity of SMI becomes the dominant picture of mental illness and shapes interaction as it produces a number of beliefs about people with SMI.

### **Beliefs of the ER nurse about people with serious mental illness**

A pervasive system of beliefs regarding people with SMI act to segregate this population and create a sensitivity when working with them. The belief that people with SMI are difficult to understand, dangerous, frustrating, and often time-consuming created a context for interaction where ER nurses treat people with SMI differently or distance themselves from them. This system of beliefs is developed out of experiences with patients displaying symptoms of their illness as well as through a process of exchanging beliefs with one’s peers.

Beliefs and experiences with mental illness were explored with participants of this study. While one nurse described growing up with a mentally ill family member, the other participants all described having little or no personal experiences with SMI prior to nursing. Taking part in psychiatric rotations during nursing school was delineated as the first real contact with SMI for most subjects. These experiences were described as creating fear: “I remember in nursing school going to the [psychiatric hospital], probably my first experience with mentally ill people, and being fearful more than anything.” Another subject said, “When I went to nursing school and I went through one of my

psych rotations, I went up to the state hospital for three days, that was a scary place.”

These experiences were also described as bringing an awareness of the devastation that can be caused by psychiatric illness on a person’s life:

My rotation at the psych hospital was quite an eye-opening experience. I don’t think I was aware of the extent of people in general who suffer from mental illnesses and the impact mental illness has on their lifestyle. I just remember talking to a lawyer who lost his ability to practice because of his mental illness and talking to a schizophrenic who was telling me about when he started having the onset of symptoms and just how much his life was completely changed because of the illness.

Prior to working in the ER, nurses reported having limited knowledge and familiarity with mental illness as well as a sense of disconnect between mental illness and the traditional ways of looking at and treating physical illness. One nurse said:

We would get patients that were suicidal or who attempted suicide or overdoses . . . thinking maybe they were not having a medical reason for being in the hospital . . . you think, why are you here, why are you doing this to yourself, [we were] not understanding the concept of why this happens . . . [you are used to treating] medical problems, something that is curable with an antibiotic or something and they get better and go home.

Working in the ER brings exposure to many new situations and people who are unfamiliar, something that can create uneasy feelings. Dealing with a person with SMI was seen as one of the particularly difficult tasks:

When I started here, I was pretty naïve. . . . I saw a lot of stuff that I had never seen before. I had never been around . . . these kinds of things, let alone people with mental illness, so I think my initial reaction was that I was scared of them. I didn’t know [about mental illness] and I didn’t want to talk to [mentally ill people] because I was shy. Working here you see the way that the other staff treats them and so I kind of learned to be biased that way.

Part of the process for new ER nurses is to learn the established protocols and expectations for managing different types of problems. Learning these protocols

increases skill level, establishes a sense of emotional competence to deal with pressures of the job, and demonstrates to peers that one is able to meet the requirements of others in their classification. The use of protocols also helps alleviate the feelings that come with the different situations encountered; expectations are established, and all you have to do is follow the protocol to competently deal with the situation. One of the difficulties ER nurses describe in dealing with people with SMI is the inability to follow a scripted protocol. One nurse reported:

I don't remember getting any education about how to deal with mentally ill people on the job except for experience. We have protocols for chest pain and abdominal pain and flank pain; we can go in and just get started and do what we do. It is much easier for us to take care of. There is not that kind of step-by-step process for someone with a mental illness, so it's more difficult.

Interaction with one's peers provides a less formal instruction on how to manage situations and patients by following what others do under certain conditions. Through this type of learning, beliefs about various classes of patients and how to manage them is handed from nurse to nurse. This exchange of beliefs acts to further inform one's expectations and socializes one into the identity of ER nurse. The interaction of exchanging stories, as described by one ER nurse, is an example of how this process takes place:

Well obviously you hear stories . . . when I first started I remember it was scary for me. I felt like my safety and other people's safety was at high risk. That was something I never really experienced before where I felt uncomfortable being alone with someone. . . . I think learning, hearing other peoples' stories, helps you be aware of situations. I think I have learned to be more cautious from other peoples' experiences and what they have taught me here.

The exchange of stories demonstrates the process of socialization whereby beliefs are passed from one nurse to another, much the same way that people in society in

general learn what is accepted by their culture and what is to be rejected. Interaction with one's peers in the ER promotes a culture that has its own set of beliefs related to how certain types of individuals are viewed and what behavior is acceptable.

The beliefs related to people with SMI were explored as well as what actions are seen arising from these belief systems.

### Difficulty understanding SMI

Several nurses interviewed described the difficulty they had comprehending mental illness in comparison to a physical illness. Patients who primarily manifest symptoms affecting behavior, thought, and emotions were often described as difficult to understand. Part of the lack of understanding may be related to how ER nurses are trained to think and prioritize care, based on established protocols:

I don't think people find mental illness and physical illnesses as equal diseases, if that makes sense. . . . I think it's because you learn ABCDs, so you are thinking if this person does not have a problem with his ABCDs, then he can go on the back burner a little bit.

Some nurses viewed symptoms of mental illness as willful or purposeful compared to the symptoms of physical illness, over which the afflicted person has little or no control. Mental illness was seen as something of an enigma that does not respond to traditional means of intervention, and nurses knew less about mental illness than about other types of problems encountered in the ER:

You are uncomfortable with those kind of people because you don't know or understand [mental illness] that well. For example, a heart attack is pretty straightforward, but there's so much unknown about mental illness and in the ER we don't spend a whole lot of time trying to get to know it—so unless there is some outside force driving you to get to know it and understand it, I don't think it's focus for ER nurses.

This sense of being uncomfortable with the challenges presented by people with SMI was a common problem and has been identified in other studies. Studying the experiences of mentally ill patients and staff in a general hospital setting, Liggins and Hatcher (2005) found a theme of “relating mind to matter” to explain the difficulty seen in integrating not only psychological and physical symptoms, but the relationship between the patient with SMI and the health provider without a psychiatric specialty. The lack of knowledge and understanding of mental illness seen in comparison to people presenting for reasons considered to be more a part of the ER nurse’s role, such as chest pain, was repeated often.

I feel a lot more comfortable with chest pain than I do with mental illness. Just because I know, I know the steps on chest pain, I know exactly what to do. With mental illness I don’t have a clue.

The lack of understanding and education that comes for some ER nurses when taking care of someone with mental illness may create a sense of exposure that ER nurses are uncomfortable with. Being in a position where you are required to care for individuals when you have little understanding about their condition leads to a sense of vulnerability over potentially making a mistake, a feeling of incompetence, or fear of failing the patient, as was explained by one nurse:

Sometimes I am intimidated by [mentally ill patients], because I don’t know what to say to them, especially if they are not compliant on their meds, when you know someone is having hallucinations. . . . I get very scared because I don’t even know how to approach them. I don’t want to say anything that will make them think I am judging them, I don’t want to say anything to make them go off, so sometimes I am pretty nervous around them.



Being in this type of situation can challenge the sense of security and confidence that is valued by ER nurses and may produce a fear of failing to be able to make the appropriate intervention.

### People with SMI as dangerous

Another fear-producing feature related to people with SMI is the frequency that ER nurses are exposed to violence and other abnormal interactions. ER nurses participating in this study described having an awareness of violence caused by people with SMI when they are symptomatic; such awareness develops through experiences in the ER as well as from stories exchanged with other staff. Each nurse interviewed described witnessing acts of aggression by people demonstrating symptoms of mental illness. One commented, “One of the scariest parts of coming to the ER to be a nurse is to be with people who are a little out of control at times.”

Witnessing acts of aggression and violence by people displaying symptoms of mental illness sensitized nurses to the potential threat that people with SMI may pose. Such sensitivity created apprehension and the need to approach patients with the threat of danger in mind: “I bring up schizophrenia a lot because [patients] are hearing things and sometimes they are seeing things, and I don’t want to be on the end of a hallucination.”

The need to approach patients with SMI cautiously because of potential violence is seen as a belief that influences interaction for people with SMI. Having to approach a patient and make an informal assessment for potential hostility changes the context of interaction. New elements are introduced as the ER nurse watches for potential violence and takes measures to ensure his or her own safety:

I just get a vibe from some people who aren't stable and may be violent or aggressive toward me, and those people make me very uncomfortable. I step further away and I probably ask fewer questions—just those I absolutely need to.

While people with SMI are often stereotyped as violent by the general public (Angermeyer & Dietrich, 2006), experiences and stories in the ER seem to heighten the awareness of potential violence. Winstanley and Whittington (2004) reported 30% of ER staff had at one time experienced an aggressive act toward them. Another study reported that 40% of all acts of aggression in an ER involved patients there for psychiatric clearance (Paine, Winiarski, & Salness, 1991). Exposure to the potential for violence becomes a factor that shapes interaction through a process of defining the situation and creating a need to assess for the possibility of dangerous behavior. If such behavior is suspected, then distancing or avoiding interaction results:

I try to get a feel for [mentally ill patients] and after seeing if . . . there is any hostility, I'm way cautious and I tend to stay closer to the door and back away because I have seen a few things that made me nervous with people.

The fear of hostility and violence as a significant factor in shaping interaction with mentally ill people has also been reported in other studies. Reed and Fitzgerald (2005) reported that more than half of the sample of nurses from a general medical unit had negative attitudes in caring for people with a mental illness. Most participants identified a general dislike of caring for people with a mental illness that was due to fear of violence as well as a lack of support and training for undertaking that role.

#### People with SMI as source of frustration

In addition to fear, ER nurse participants discussed feeling frustrated working with patients who have SMI. Part of the frustration was due to seeing the same patient

repeatedly and feeling helpless to intervene or change the “revolving door” effect—coming to the ER repeatedly for the same problems, usually because of poor follow-up care (Ledoux & Minner, 2006):

We see the same people over and over, and you just wonder, is this ever going to end . . . are we ever going to be able to get this person past this point and be able to help them? It is hard, because we only see the people who don't improve. We don't see those who actually go on to live their lives and do okay.

This frustration was repeated in several interviews and coincided with attributing the repeat visits to irresponsible patient behavior and unaccountability. When this judgment was made about accountability, it became more difficult for the nurse to deal with such situations:

I get kind of fed up with the ones who come in every single day and are not taking their meds and not following through with their appointments and not compliant in any shape or form. . . . Why are you here again when we have given you every resource available, you have your meds, you have counseling sessions—why do you keep coming back? So I sometimes struggle with the repeaters who are not doing anything to help themselves.

The inability to help such patients improve results in feelings of helplessness and a belief among the ER nurses that regardless of how they interact, the patient will end up returning to the ER. Nurses felt that these patients warranted limited investment of their efforts because the possibility of changing the patient's behavior seemed futile.

#### People with SMI as a drain on resources

Finally, ER nurses felt that patients with SMI are a drain on the healthcare system in general as well as the resources of their department. Patients with SMI were identified as people who were not likely to be productive members of society and who were taking advantage of the healthcare system:

[ER nurses would view mentally ill patients as] down several notches from where they are. They assume [mentally ill patients] don't have a job, don't contribute as a productive member in society, and so I think they kind of treat them poorly.

On the level of nurses having to manage these patients' needs, the patients were identified as time-consuming and disruptive to the demands of a busy ER. Patients presenting for mental health treatment in the ER often require extended stays. Slade, Dixon, and Semmel (2010) reported the average length of stay was 42% greater, or 1.25 hours longer, for patients presenting for psychiatric reasons as compared to those presenting for medical reasons. The disruption of the process of moving patients along created by people with SMI was a meaningful issue for the study participants:

When I am charging and my concern is the flow of the department, it can sometimes be a frustrating thing because the process through the ER is a little bit slower with [patients who have] mental illnesses. You have to have somewhere to [send] them to and sometimes that is harder to find. I wouldn't say it's necessarily more work, but sometimes it creates more of a frustration because it slows the process of the in and out, trying to move people through, trying to move people along.

Another way that people with SMI were seen to deplete the resources of the ER was through the requirement to keep them safe. Having adequate staff or rooms to ensure safety created a burden not seen in other patient populations:

I feel like our department is maybe not set up very well as a safe place to put these patients. . . . We don't really have very many rooms within sight. . . . I can't be with this patient, I can't have someone sit there and watch the patient. I think that sometimes your resources are limited to the point that you don't feel like you can provide the safety that you should to these patients.

The extra burden that patients with mental illness cause in the ER through using high amounts of resources creates a belief that this patient population is not well suited for treatment in this type of situation. Mavundla (2000) found similar results using

semistructured interviews to describe the general hospital nurses' perception of working with mentally ill people. Common themes that led to overall negative experiences for the staff included the disruption of normal duties and routine that came from having a mentally ill patient on their unit, the impact of low self-confidence in working with the mentally ill, and the inability to develop a relationship with the individual due to perceived fear, despair, and frustration. These findings resonate with the depictions from subjects in this study and provide further awareness of the difficulty that the ER nurse may find working with people who have a mental illness.

As a result of the beliefs that ER nurses identified about people with SMI, practices of social distancing were seen as a strategy to deal with the emotions that came from these beliefs. Social distancing refers to the routine of avoiding contact with people who have undesirable traits and has been linked to public behaviors with serious mental illness (Link et al., 1999). Avoidance of interaction or having minimal interaction was described as behavior that supports the general regard some nurses have for people with SMI:

They kind of dissociate, so it's not really counted like one of their patients. They don't go in and introduce themselves or offer them a warm blanket or whatever they do with their patient with abdominal pain or chest pain or whatever. . . . If it's somebody that we see all the time, [nurses] don't want to go in and do an assessment. I have seen some nurses completely avoid going in that room at all. Unless the doctor writes a specific order for a medication or something that requires them to go in the room, they won't go in the room, period.

Avoidance or distancing creates a condition in which effective communication cannot take place and leaves the patient with little opportunity to interface with the healthcare provider. Avoidance of interaction is seen to drastically shape the healthcare contact and limit potential positive outcomes for both the patient and provider.

## Discussion

The stigma of mental illness is seen in this study to have a negative influence on healthcare interaction between ER nurses and people with SMI. Mental illness as a construct of social discourse is inlaid with symbolic meaning that acts to define how people with SMI are viewed and related to. The socially defining characteristics of mental illness create an individual that is looked at differently in the healthcare setting through an interpretive process based on conceived or stereotyped schemas. These conceptualized ways of looking at people with SMI come from experiences seeing them when they are in crisis situations or from recounted experiences from others. As a result of the conceptualization of people with mental illness, practices of social distancing and avoidance occur in the healthcare setting.

This finding was supported by the themes of role incongruence, identity overshadowing, and segregational sensitivity. Role incongruity refers to the poorly aligned identity and skills of the ER nurse with patients presenting with SMI in the ER. This role misalignment occurs from the lack of demonstrated need of patients presenting in the ER with SMI for the valued skills of the ER nurse. ER nurses identified their role and identity as having little to offer patients with serious mental illness due to the value placed on skills that are oriented to care for patients of a highly critical nature. They also discussed having low confidence in their ability to impact a person with SMI and in some cases feared making the patient's condition worse.

Nurses acknowledged that they have frequent dealings with people in the ER who have a mental illness; however, the dominant perception of people with SMI is the person presenting for psychiatric crisis, who is highly symptomatic of their illness—a situation

known as identity overshadowing. This perspective of viewing mental illness as expressed by unusual behavior limited the nurses' ability to focus on providing medical care to stable members of this population. This characterization of SMI also falsely identifies people with unusual behaviors as mentally ill, when the reason for their abnormal behavior may result from other factors, such as substance abuse.

Segregational sensitivity is being sensitized to beliefs about people with SMI as dangerous, frustrating, and time-consuming, and difficulty for nurses comprehending psychiatric illness compared to physical illness. These beliefs about people with SMI were pervasive in this sample of ER nurses and identified features that were unique to this population. From these beliefs, ER nurses defined interactions and identified strategies of distancing and avoidance when working with this population.

These themes support the premise that the stigma of serious mental illness affects how healthcare interaction takes place and influences it in a negative direction. The interactions with SMI people are perceived as more difficult, less rewarding, and potentially dangerous.

These findings may have implications for the healthcare provider who does not have a specialty in mental health but who provides medical care to people with mental illness. Through understanding the potential pitfalls and stereotyped beliefs that many medical providers have about people with SMI, a better approach can be devised to decrease stereotyping practices. This study also demonstrates the need for further educational and pragmatic approaches to help medical providers gain increased awareness of the difficulties faced by people with SMI when attempting to get healthcare.

A limitation of this study is that only nurses were interviewed, as several people are generally involved in the care of ER patients. While ER nurses may have the bulk of contact with patients, other caregivers may have different opinions about people with SMI, which may influence healthcare interaction in other ways. This limitation necessitates additional follow-up with future investigations using other provider types to compare for similarities and differences.

This study was conducted to increase understanding of how the stigma of mental illness shapes the process of healthcare for people with SMI by looking at the mindset that healthcare workers have about people with SMI and the framework in which they interact. The study of this process was conducted using grounded theory, a qualitative methodology, and therefore is limited to providing explanation only for the population being studied. Future work will have to be conducted before a generalization can be made. This study also has a limited scope of investigation into healthcare as a social process. While there may be many factors that contribute to the difficulties that medical providers may experience through their encounters with people who have SMI, the aim of this study was to look at healthcare as a social process that can be deconstructed and understood through the symbolic nature with which society interacts. While the impact of such understanding is significant, it can in no way fully explain all the intricacies of the problems encountered in healthcare interaction.



## CHAPTER 5

### SUMMARY: TOWARD A TRANSFORMATIVE AND TRANSACTIONAL THEORY OF STIGMA AND IDENTITY

#### **Introduction**

The stigma of mental illness is theorized in the present study as a condition or classification that affects healthcare as a socialized process for people with SMI. The effect of mental illness stigma on the healthcare process is seen when viewed using the theoretical framework of symbolic interactionism. The main premises of this framework, as outlined by Blumer (1986), assert that people act towards things based on meanings that those things have for them. That meaning results from social interaction, and meanings are modified through an interpretive process. Using symbolic interaction helps to deconstruct healthcare as an interaction between individuals that come together during brief periods of time for the purpose of maintaining or improving physical wellbeing. This mutual interaction involves the association of different groups of people that possess ideas about themselves and those with whom they come into contact. Through the deconstructive analysis on the interplay between these two groups, the stigma of mental illness is seen as a detrimental influence on the process of healthcare interaction and may play a part in the overall poor health for people with a serious mental illness.

The review of the literature related to medical mortality and comorbidity for people with a serious mental illness demonstrates that this population is at high risk for comorbid medical problems and medical mortality compared to people without serious mental illness. This high rate of mortality with an overall decreased life expectancy is related to a number of reasons, such as serious mental illness itself, lifestyle factors, and system-related influences. Research on the stigma of mental illness has also demonstrated that SMI negatively influences social processes, including healthcare, by the creation of stereotyping and discriminatory behavior based on attributional processes. These attributional processes stem from a system of beliefs about the seriously mentally ill as a population and attribute certain qualities to them based on these beliefs. People then act toward the seriously mentally ill based on these beliefs at the sacrifice of individuality. The stigma of mental illness has also been shown to have labeling effects through which people with SMI internalize societal beliefs about mental illness and act on how they believe other people will view them. The influences of attribution and labeling effects reach across a variety of factors that affect the health of people with SMI.

### **Transformative and transactional effects of stigma**

Consistent with attribution and labeling theories of stigma, this study finds evidence to build toward a theory that the stigma of mental illness acts as a construct that transforms a person's identity from both the internal perspective as well as through the perspective of others. Mental illness as a socially understood concept carries strong beliefs and implications that make it a distinguishing concept in social discourse. Mental illness changes a person's identity through the internalization of the distinct meanings of this condition into a person's sense of self. Mental illness also changes how people with

this condition are perceived by others through associations of the negative beliefs ascribed to this condition. This transformative process reflects the socially understood meaning of mental illness using both intrapersonal and interpersonal dialogues to create an identity that is devalued. This devalued identity is associated with stereotyped beliefs of the mentally ill population.

#### Transformation of the sense of self

In response to being designated as mentally ill through the process of being given a diagnosis and requiring ongoing treatment, individuals are confronted with the idea of what this designation means to them from the perspective of how society and others will now view them. Mental illness as a socially understood condition is often credited as a socially devalued label that conjures up images of violence, incompetence, and other negative meanings. Having an understanding of these beliefs and their social relevance creates the formidable challenge to incorporate these concepts into one's sense of self and establishes the situation where this label becomes an identity that is concealed or avoided. As one individual with SMI put it when describing her pre-illness beliefs about mental disorders: "Mental illness was taboo . . . it wasn't something I would have to deal with . . . or at least that's what I thought."

Over time, the label of SMI becomes gradually accepted as an identity that becomes part of an overall identity structure. The gradual process of incorporating this identity brings with it a socially understood position where the values, mores, and qualities that are traditionally assigned to mental disorders have now been subsumed. While individuals may or may not subjectively agree with these qualities assigned to SMI, they become subjected to society's way of looking at mental illness. Through

interaction with others and society in general by way of media, people with SMI define how they are viewed through the ability to see themselves from the position of others and society. This becomes the identity and position from where they perceive their social value and where they define their identity in social interaction. This transformed sense of identity becomes a part of the self that is often concealed from the public as much as possible to prevent being subjected to stereotypical beliefs as one person explained: “If you tell some one, yah I am mentally ill, they immediately think, oh, he is going to kill me.” The transformed identity also creates a stance of how to define the situation and what responses are appropriate given a set of circumstances. For example, people with SMI in this study identified different ways of approaching an interpersonal situation if their mental illness was known or not known. People who participated in the study defined places such as the day-treatment center as places where they were able to freely discuss mental health issues without fear of falling out of favor. This stood in opposition to other places, where disclosure of one’s mental illness led to social ostracism.

### **Transactional identity and mental illness stigma**

The stigma of mental illness also transforms identity from the perspective of others through interaction. Interpersonal interaction is a means by which beliefs and expectations about mental illness are transmitted between others. Through interaction with others who do not have serious mental illness, the person with SMI gains an understanding of society’s view towards those with SMI. Interaction between people who share the identity of serious mental illness also provides another perspective on SMI as an identity. A sense of understanding is gained through connecting with others who understand what it is like to be mentally ill and the challenges it creates in a larger society

that devalues people with mental illness. This understanding comes through the process of sharing experiences that provide a common background from which people of all different types of circumstance are able to unify. This common understanding allows people to exchange ideas and experiences with others who are not mentally ill. Through the exchange of ideas and experiences, further definition of how one fits into the larger society is gained. This insider perspective also informs the individual what to expect when interacting with the outsider group and what strategies may or may not be effective to dissuade unfavorable treatment. Many people in this study identified having common experiences with others who were mentally ill, such as the distancing of friends and family once a person's mental illness was learned. This common experience served to instruct how mental illness is to be disclosed and under what circumstances disclosure should take place to avoid the future loss of relationships.

Another way in which mental illness transforms identity is seen in the person who does not have a mental illness but who has opportunity to interact frequently with those that do. Through interviewing ER nurses who have regular contact with people who have SMI by means of their employment, an identity is seen in reaction to the patient with SMI. ER nurses identified having difficulty dealing with SMI people who were experiencing symptoms because of a lack of knowledge about mental illness in general, lack of skills to deal with abnormal or unusual behavior, and fear of violence. In response to the difficulties that were encountered in taking care of people with SMI, an identity of "we're not psych nurses" was the common approach that helped explain their position. This response was followed by behaviors that included avoidance or a sensitized approach for fear of danger.

Interactions between ER nurses also served to instruct the nurse how to approach patients with SMI. ER nurses identified the practice of telling stories about their interactions with certain patients as a major way of learning from other nurses about potential difficulties when dealing with people who have a mental illness.

Interpersonal interaction is a way by which the stigma of mental illness is transmitted between insider and outsider groups, but also within these groups. Through interpersonal interaction, identities are formed and maintained that create the basis for defining future interactions and exchanges. This transactional means of identity transformation takes place as an ongoing process and is affected by individual and societal forces.

The effects of both intrapersonal and interpersonal influences create a dynamic situation laden with potential social breakdown. Intrapersonal changes in an individual's identity may lead to a negative valuation of one's self and can result in the perpetuation of stigmatizing beliefs, stereotyping, and ultimately discriminatory behavior. The transformative nature of SMI is seen in the challenges that occur as the SMI address their healthcare needs as well as the with the medical care providers with whom they interact in the context of healthcare.

### **Healthcare interaction for people with serious mental illness**

Healthcare as a social process is seen as a series of interactions between people seeking care and those who provide it. Healthcare as a social process may be affected by the same social pressures and influences that are present in society at large. These influences are felt to shape healthcare interaction for people with SMI due to the prominent beliefs that are associated with mental illness. The beliefs connected to serious

mental illness help to define how people with SMI are viewed from both interpersonal and subjective perspectives. The transforming and transactional effects of mental illness stigma on healthcare as a social process are seen as dominant and undesired.

### SMI as a dominant identity in healthcare

Mental illness transforms how a person's identity is perceived by others through interpersonal interaction. This process is exemplified by the study of how ER nurses perceive people with serious mental illness. Nurses working in ER settings have frequent contact with SMI people through their employment and are often exposed to people with mental illness at times when their symptoms are most prevalent. This presentation can be dramatic and often leaves a lasting impression. That impression becomes the dominant means of identifying people with SMI in the ER and overshadows other presentations of mental illness, such as the SMI patient whose symptoms are well controlled. This highly symptomatic presentation becomes the identity that is associated with serious mental illness. Other patients who display aberrant forms of behavior in the ER, even when not related to mental illness, may also be thought of as mentally ill due to the influence of this predominant way of viewing serious mental illness.

SMI patients who exhibit dramatic symptoms become a benchmark of what to expect from future interactions with this type of patient. Additionally, nurses exchange stories about their experiences. This perception helps the ER nurse construct a way of relating to the person with SMI. In this study, ER nurses developed a way of looking at patients with SMI as having difficulty understanding mental illness compared with physical illness and feeling people with SMI are dangerous, frustrating, and often time-consuming.

When nurses were able to identify other perceptions of people with SMI, these came from experiences outside the ER, such as having a family member with mental illness or having opportunities to interact with the mentally in the community, where they were seen as functioning members of society. These outside experiences were able to foster a different perception of people with SMI once the identity of ER nurse was changed to that of community or family member. The interpersonal exchanges created through these different settings allowed for the ER nurse to see people with SMI as more than just a patient presenting with odd or disruptive behavior, but as a functioning person in a family or the community. While these different ways of viewing people with SMI created an alternative way of looking at these types of individuals, only the nurse who assisted a family member through treatment for a mental disorder acknowledged any change in the way she interacted with SMI patients in the ER.

Although a person's sense of who they are consists of several different identities, such as those associated with the roles they perform and the groups they belong to, each of these identities become important under different contexts. The same is true for identities that are assigned by others. While a given situation may require identification of a certain characteristic of a person and subsequent assignment of this identity, in other situations it may be irrelevant and eclipsed by another identity. This way of modifying identity through context is useful in understanding Blumer's (1986) premise that individuals not only construct meaning through interaction, but also modify this meaning based on an interpretive process. This contextually based identity is also relevant in the discussion of how SMI identity creates problems in healthcare interaction.



### SMI as an undesired identity in healthcare

Healthcare interaction for people with SMI is a unique experience. In the context of healthcare interaction, people with SMI are unable to use common strategies of concealing or avoiding disclosure of their mental illness because it is seen as necessary information for medical providers. Without the ability to conceal their mental illness, people with SMI are left vulnerable to the beliefs and practices of their healthcare provider. While most people with SMI felt that medical providers were less likely to employ stigmatizing practices, many individuals identified feeling either stereotyped or discriminated against at one time or another by a medical provider.

Out of this vulnerability to unfair treatment, people with SMI attempted to downplay the relevance of their SMI when seeking treatment for physical problems. Many individuals felt that their SMI was not relevant in seeking out treatment for a physical illness.

While a person's SMI may not be felt as relevant in the context of receiving medical care, many patients with SMI felt that their mental illness became an overriding identity in some situations. People with SMI said medical providers treated them differently, got distracted by the mental illness, and looked at them as less competent and drug-seeking.

As a result of the perceived susceptibility to maltreatment, people with SMI in this study identified avoiding healthcare contact until symptoms were obvious so that they could not be dismissed as some type of mental illness behavior. They also described frequent changes in their medical providers out of the need to find a provider that was

perceived as understanding and would not blame physical problems on their mental illness.

From an interpersonal perspective, people with SMI also said that medical providers treated SMI as reducing a person's credibility when addressing medical problems. They said that disclosure of their mental illness created situations in which medical providers appeared uneasy, especially when discussing matters related to mental illness. In some cases they felt that this perspective of mental illness led to some of the beliefs and unhelpful practices that they were accustomed to seeing in the context of healthcare. One patient gave the following example of how she was treated for a particular medical problem:

I tried somebody who was very sweet and kind as can be and great with the depression stuff, but I really thought he was incompetent. I couldn't believe his care or the way he was just making up stuff. . . somebody called it "guessterology" or something. . . . I don't know if he got too focused on my mental health issues or he thought I was just a stressed-out lady suffering from anxiety. I had a massive uterine fibroid the size of a honeydew melon, and it took a long time to diagnose. It was huge and I'm not a big enough person to accommodate a honeydew melon. . . . First the doctor thought I was constipated, then he thought it was just stress.

These types of interactions were described by participants as common occurrences and served to entrench the understanding of mental illness as a devalued identity in the medical setting.

Using the framework of symbolic interaction to look at healthcare interaction provides an opportunity to view healthcare as a social process where both the person with SMI and the medical caregiver come to the interaction having preconceived beliefs about each other. These beliefs are a result of the intrapersonal and interpersonal dialogues about mental illness as it is socially understood. Beliefs about mental illness act to

sensitize each of the participants to the ability of mental illness to disrupt the process of medical care. The patient has to interact with people who may view him or her as different, less capable, or incompetent. The caregiver's is concerned about the possibility of being exposed to dangerous, abnormal, or unacceptable behavior. These elements transform the interaction and identity of both participants.

### **Implications**

This study helps to define how the stigma of mental illness affects the healthcare process for people with SMI. Healthcare is viewed as a socialized process that is vulnerable to the influences of outside pressures, such as those created by the social understanding of stigma. The stigma of mental illness is seen as a concept that is able to transform how people view themselves and how they perceive others will view them, including in the arena of healthcare. Medical providers, such as nurses, also form identities in relation to their role in treating people with SMI and are also capable of perpetuating negative beliefs about mental illness through interpersonal contact with people who have SMI.

Identity formation is seen as something that is constantly undergoing transformation through ongoing interactions with others, such as those seen in the ER. The stigma of mental illness is seen conceptually as something that acts internally to transform this identity but is also something that acts dynamically through ongoing interactions with others. These ongoing interactions further construct identity through everyday relations with one's self and others.

The findings of this study are relevant to healthcare as they seek to inform and provide insight into the problems faced by people with SMI seeking medical care as well

as the providers entrusted with taking care of them. These findings demonstrate how a socially constructed factor such as the stigma of mental illness acts to influence the seeking of healthcare as well as interaction with medical providers. The results of this study also show that the high rate of medical morbidity and mortality associated with serious mental illness is related to many different factors and that approaches to improve healthcare should focus on reducing the effects of stigma.

By adding a more specific theory about stigma in healthcare interaction, increased awareness of the influence of this construct can be appreciated and used to create changes for people with SMI seeking healthcare. Stigma is not just about beliefs and attitudes, but is part of how we construct our identity through interactions. Past efforts to reduce stigma have focused on educating people about mental illness. The present study acknowledges education as meaningful, but in order to address the negative effects of stigma, interventions must also be tailored to affect how we interact with individuals with SMI. Interventions may include helping people with SMI understand the concerns of medical providers and how to present oneself during a visit with a medical provider. Medical providers may also benefit from interventions that allow them to interact outside of a medical context with patients who have SMI in order to allow them to have different views of people with SMI. Both parties may also benefit from coming together to understand each other in a forum outside of healthcare interaction. Future studies should focus on interpersonal constructs that lead to stigmatizing beliefs and behaviors between patients with SMI and healthcare providers and what may help improve the process for both parties.

## APPENDIX A

### SAMPLE QUESTIONS FOR SERIOUS MENTALLY ILL PARTICIPANTS

1. Can you explain to me what you thought about mental illness before you were diagnosed?
2. What was the experience like when you first sought out treatment for your mental health disorder?
3. How has having a mental illness influenced how others treat you?
4. How do you go about telling others you have a mental illness?
5. When do you tell, when do you not tell?
6. How do you tell medical providers about your mental disorder?
7. What kind of experiences have you had when you talk to medical providers about your mental disorder?
8. What kind of experiences have you had after your medical provider has found out about your mental illness?
9. What kinds of things have you found helpful when talking to medical providers about your mental illness? What have you found to be harmful?
10. What kind of problems have you gone to a medical provider for? What influences you to seek out help for these kind of problems?

## APPENDIX B

### SAMPLE QUESTIONS FOR EMERGENCY ROOM NURSES

1. Before you went into nursing, what kind of experiences did you have with people who have a mental illness?
2. What were your thoughts about mental illness back then?
3. Before you started working in the emergency room, what experiences did you have working with people who have a mental illness?
4. How has working in the emergency room shaped your view of what it is like to work with people who have serious mental illness?
5. What things have you found challenging working with a person who has a mental illness?
6. What rewarding things have you found working with patients who have mental disorders?
7. How do you find out about a person's mental illness?
8. How important to you is it, that you know if your patient has a mental illness?
9. Are there things that you do, or that you see others do when working with someone who has a mental illness?
10. How has the staff in the emergency room shaped your view of people with mental disorders?
11. What does it mean to be an ER nurse?

12. What do you enjoy most about working in the ER?
13. What skills and abilities do you or your colleagues value most?

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